

PROCURING BETTER CARE IN LONG-TERM CARE FACILITIES

PROCURING BETTER CARE IN LONG-TERM CARE FACILITIES:
EFFECTING CHANGE WITHIN THE COMMUNICATION STRATEGIES
TO WHICH NURSES AND PATIENT FAMILIES PRESENTLY SUBSCRIBE

By

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ABSTRACT

In short, this work investigates the existing tensions between families of long-term care patients and their nurses. Insofar as these tensions directly result from poor levels of care that are currently administered in long-term care facilities, attention is drawn to how such inadequacies can be remedied through an in-depth exploration of inadequate resources, surrogate decision-making standards, the gendered nature of nursing, and the stigmatization of disability. By increasing social support and setting up non-confrontational communication strategies, the tensions between nurses and patient families are alleviated but also suggest the possibility of extending these strategies to areas in nursing outside of long-term care.

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Introduction

I begin by summarizing the principal findings of a study conducted in 2002 by Linda H. Aiken, Sean P. Clarke, and Douglas M. Sloane:

Upon examining 2784 nurses in 96 Ontario hospitals, and 601 nurses in 33 British Columbia hospitals, it has been determined that 14.4% of nurses in Ontario and 15.5% of nurses in British Columbia rated the quality of care on their unit as fair or poor. In addition, 45.6% of Ontario nurses and 49.8% of British Columbia nurses reported that the quality of care in their hospital has deteriorated over the past year, while 27% of Canadian consumers rated their last hospital stay as fair or poor.¹

Deficiencies in hospital care—while easily passed over by outsiders or those staying in hospitals for short periods of time—can be devastating to long-term care patients and their families over the course of their hospital experiences. The inadequacy of care provided to patients who make hospitals their permanent residences—specifically, those requiring the highest levels of care on account of severe mental and physical disabilities—is the central problem my work has been written to resolve. And, in seeking out answers as to why patients of such limited capacities are not receiving good care, I shall make the case that what has caused poor hospital care in Canadian hospitals pertains, primarily, to the following factors: (1) the gendered nature of nursing; (2) the lack of certainty in surrogate decision-making standards; (3) organizational and social support shortages for nursing; (4) a societal failure to value nursing as meaningful work; and (5) the stigmatization of disability. Insofar as nurses are unable to meet the needs of their patients and patients suffer as a result of the limitations imposed upon both parties by each of these issues, in situations where families act on behalf of the patient, conflict

over what constitutes adequate care can often arise between nursing staff and family members. Surely every family wants their loved one to receive the best care possible, and witnessing substandard treatment would, understandably, have family members up in arms in an effort to demand better treatment for their loved one. But, as long as nurses' needs are not taken up socially, and women are not remunerated for the nursing they perform, individual care needs of patients cannot be successfully or sensibly fulfilled and conflict between nurses and their patients' families is inevitable.

I propose that in order to provide better care for patients in long-term care facilities and alleviate the concerns of their families, we must find resolutions for each of the causal factors I just outlined, all of which, I have come to believe, shape the inadequacy of the treatment patients receive. In particular, I call attention to the importance of establishing non-confrontational *dialogic negotiations*² between all those who participate in the care of the patient. It is my view that, when it comes to those families of long-term care patients, treatment options and decisions would better be attained through a more collaborative, non-hierarchical effort. For adopting an approach that encourages positive discussions between nurses and families will not only help to bring nurses and families together in less confrontational settings, but will also help to elucidate and, perhaps, shift the expectations both parties often place upon one another. Currently, while dire patient circumstances lead to family occupancy of surrogate decision-making roles and where next of kin are entrusted to act on behalf of their loved one, the lack of clarity in surrogate decision-making standards can make it especially difficult for families to make decisions without added criticism or coercion from nursing

staff. It is the confrontational nature of these interactions between families and nurses that seems to hinder any movement towards collaborative effort where the central focus of both parties can be directed towards improving patient treatment—a strategy that, I believe, when it comes to long-term care, is far more efficient and effective than the established confrontational and argumentative pattern in nurse/family conversations.

Arriving at the identification of the inadequacy of patient care and my plan to concentrate exclusively on severely disabled patients were not prompted entirely by the findings of the study conducted by Aiken et al. Rather, my reflections were provoked in part by personal circumstances that made questions surrounding the adequacy of long-term care profoundly prominent for me. Upon completing a graduate course a year and a half ago that focused on dependency work³ and the lack of resources available to non-contractual and contractual care workers, I submitted my name to be matched up at a local hospital with a family requiring additional support, assistance, and aid in the negotiation of care for a severely disabled family member. In working with the family to which I was assigned, it became clear to me that something must be done to ensure that better care is provided for those who take up permanent residence in hospitals and, additionally, that family suggestions for care be incorporated into the ethic of care that nurses provide.

The onset of any illness or disability can be debilitating for any family and learning that a loved one may never regain the full range of capacities they once held can test a family to its limits—particularly when the limitations imposed by the disability require that the family member no longer live at home but, instead, must take up

permanent residence in a long-term care facility. It is out of my work with ‘Billy’—a long-term care patient of severely limited capacities—that I came to the realization of just how inadequate and poor the level of care in long-term care facilities can be. In listening to the concerns of Billy’s family (as the quality of his care was frequently compromised), it became clear that they assumed that the neglect Billy often endured was on account of what they described as displays of laziness or insensitivity in the character of his nurses. I can recall several instances where his family referred to the nursing staff as failing to exhibit ‘honour’ in their work and many other times when his family would engage with other families from Billy’s floor in conversations that focused on the incompetence and incapability of the nursing staff to provide, what the families deemed to be, ‘mindless’ work. Whilst I understood the anger in their accusations, in witnessing the additional stress and sadness poor levels of care caused for Billy’s family, I began to wonder, to what extent is the care that patients in long-term care facilities receive actually a function of nurse ‘laziness’ or ‘insensitivity’? For as I began to see it and as Aiken et al. describe, nurses were regularly assigned more patients than they could rightly manage. The shortage of staffing levels in Ontario and British Columbia has led, on average, to 7.1 ± 2.2 and 7.0 ± 1.9 patients assigned per nurse per shift in Ontario and British Columbia respectively (Aiken et al., 10). On Billy’s floor, nurses were often unavailable or difficult to track down when Billy required assistance. And, when they could be found, if they were ever away from their patients (i.e., on lunch, speaking with other nurses at the nursing station, etc.), then his family regarded their taking a break to be unacceptable when Billy was left in such an unkempt condition. The central source of the perceived

‘laziness’ or ‘insensitivity’ Billy’s family would associate with his nurses; however, I argue it is not in fact due to a blatant disregard for the needs of their patients. Rather, I believe it is as a result of assigning too many patients to each nurse at a time, the lack of support they receive, and the tendency for their work to leave them feeling overwhelmed, underappreciated, and unfulfilled. But whether families misinterpret the reasons that back the inability of nurses to provide long-term care patients with adequate care, the fact remains that patients are receiving bad care and, so, something must be done in order to improve the quality of care patients just like Billy presently obtain.

It is those experiences with the family that I worked with for the past year and a half that have brought me here in an attempt to seek out how we can procure better care for persons with acute disabilities living in hospitals. The point and purpose of this project is to provide answers to why long-term care patients aren’t getting the care they warrant so that the intense opposition between families and nurses that bad care creates can be avoided. It is my hope that through in-depth restructuring of the present roles of nurses and families in long-term care, improving representations of disability, clarifying surrogate decision-making standards, and offering nurses access to additional support, we will be able to provide nurses with what they need to provide better care while, at the same time, making the lives of families living with disabilities less stressful.

In the first chapter, I will consider a variety of ethical questions that arise when determining what constitutes proper care for patients unable to voice their own interests. In part, determinations of good care require answers to the following questions: (1) who is to decide what is best for the patient when she cannot speak for herself? (2) Who

should make treatment decisions? And, (3) whose voices and points of view ought to be heard? I shall argue that formulating responses to each of these questions involves the application of surrogate decision-making standards. I will consider current approaches to surrogate decision-making - the best-interest standard and the substituted judgment standard - and make the claim that each of these falls short in matters where patients suffer from long-term disabilities. I shall offer as an alternative, familial medical decision making, where those closest to the patient are morally entitled to confer with nurses over all matters of care so that joint treatment decisions can be reached. In addition, I wish to consider in this chapter how we can add to the benefits of this new surrogate decision-making standard by developing an ethic of care that focuses on the particularity of each patient's illness, social location, and cultural circumstances. I will argue that recognizing the individuality of each patient not only helps to prevent nurses from focusing entirely on the objective medical condition of the patient, but also incorporates a certain level of safety and attention to the patient that improves the quality of her experiences of hospital life. This attention, as I see it, is vital to the possibility of improvement in long-term care and the fostering of a productive and positive relationship between nurses and families. And, it is within this context that I will begin to describe in greater detail my experiences as a volunteer caretaker/mediator for 'Billy' and his family. It is on my involvement with Billy, his inability to voice his own needs, his family, and his nursing staff that I base my analysis of present nursing practices and prescriptions for a better ethic of care for long-term patients. From my perspective, coming to know Billy the way I now do has helped me to relate to him as a person who is much more than simply a body demanding constant

medical attention. As I shall argue in this chapter, recognizing patients as persons which, in Billy's case, necessitates direct communication with his family members improves his level of care and ensures that everyone feels included in all aspects of his day-to-day care and medical treatment decisions.

In coming to understand what hinders the possibility of adequate care in long-term care facilities, I argue that such inadequacy is, in part, due to a lack of sufficient support for nurses. Part of the problem with nursing is that it is linked up with forms of non-contractual caretaking work and viewed from what Jennifer Parks describes as, “a voluntaristic model, where women freely and lovingly do care work as a ‘labor of love’” (Parks, 494). Chapter 2 will examine the sexual division of labours of care, wherein, as I will argue, contractual care work is traditionally delegated to and strictly imposed on women. As a result, nursing is anything but voluntary or gender-neutral. Quite rightly, Eva Feder Kittay has argued that societal expectations prevent women from entering the public sphere as the free and independent equals that mainstream theories of justice presuppose them to be. Insofar as nurses secure the rights and benefits for [their] charges (Kittay, 91); this comes at a cost to nurses' own rights and interests. And, while it may seem that a decision to forgo one's own interests for the sake of another could arguably be considered voluntary or optional when it is contractual, many of the obligations women feel towards their patients are not necessarily of their own making. Like familial caregivers, nurses are compromised. They often function in a context of hierarchical hospital policies and structures that prevent their ability to exercise their own epistemic authority. Doctors are believed to know more than nurses and their opinions often carry

more weight when it comes to the allocation of resources, funding, and responsibilities.

Consequently, requests for additional pay, benefits, leave, emotional support or assistance are frequently left unanswered.

As chapter 2 will indicate, we must concern ourselves with the implications of nurses acting as *transparent selves* individuals through whom the needs of another are determined, but whose voices are rarely heard (Kittay, 51). Nurses can (and do) find themselves in positions where they take on more patient responsibilities than they can handle, where the adoption of other-directed interests completely overpower their own. I argue that if we are to eventually arrive at a space wherein nurses can offer better care, we must first arrive at an understanding of the moral obligation we have towards them. We must concern ourselves with justice for nurses in a way that manages to balance their needs and, at the same time, provides them with the necessary resources and reciprocity they require to establish and sustain good relationships of care with their patients and their patients' families. It is here that I will introduce Kittay's notion of a *connection-based equality* as central to the development of an ethic of care that works to facilitate better care and productive conversations between all those affected by relationships of long-term care.

Chapter 3 responds to questions of how we can facilitate nursing so that the meaning attached to nurses' work is legitimately realized in both self-orienting and other-directing values. Current research reveals that all values identified in nursing work are regarded as desired for the patient's good, where the patient is the point of focus. But, as I shall argue, the capacities to grow and enjoy one's work are also essential self-oriented

values that nurses must be granted the means to actualize. I claim that these values cannot be mediated through actualizing other-oriented values, as it is a mistake to suggest that there is room for nurse self-expression in values held in relation to patients when nurses are expected to be transparent selves and put the interests of their patients before their own. Misguidedly, claiming that nurses can establish their identities as persons through the lives of their patients makes the additional support needed to replenish their care efforts seem somewhat optional. For if nurses are self-fulfilled in their careers, if their work is joyful, why ought we to pay any more attention to them than we do any other careers? Identifying the self-oriented values of nurses with other-oriented values clearly does little to resolve matters of nurse burnout, exhaustion, and feelings of meaninglessness in their careers—all of which, in some way, contribute to the inadequacy of long-term patient care. In this chapter I shall make the case that we must separate the two sorts of values so that proper emphasis can be placed on nurses' values that are self-oriented in nature.

In chapter 4, I wish to address issues surrounding the stigmatization of disability. Through my experiences with Billy, I will describe how present social attitudes encourage disabled persons to present a surface presence of normalcy so that they can be integrated back into and accepted by their communities. Insofar as disability is taken up by societies as needing to be ‘fixed’ or ‘cured’, the negative aspects of physical and mental impairments are often hidden by patients’ family members in an attempt to draw awareness to the personhood of the patient. I shall argue that focusing on disabled realities in such a manner undermines the lives of patients like Billy and encourages

continued social negligence with respect to the care and assistance to which disabled persons have access. I will also make the case for the need to separate social responses to disability from the actual physical and mental limitations of disabled persons. Taking the focus away from the impairments of disabled persons and working instead to remove disabling barriers brought about by prejudicial social attitudes toward disability facilitates acknowledgment and confirmation of patient realities. Taking representations of disabled experiences away from those who are able-bodied challenges the social construction of disability and can aid in the way that care is delivered to long-term care patients.

Finally, chapter 5 will focus on how we are to take our findings and implement them into health care practices. I will argue that insofar as surrogate consent decisions for long-term care patients involve a collaborative effort, constructing a space wherein families and health care professionals can meet to discuss their concerns is critical to the development of a proper ethic of care for all patients. I will introduce “Billy’ Network” - a network I believe ought to be implemented in the health care system in order to mediate and encourage frequent discussion between families and nursing staff. In scheduling regular meetings, assigning nursing staff representatives to each family, and taking the time to address both groups’ concerns, the perspectives of caretakers and families can be attended to in non-confrontational settings - where the care of the patient is not compromised and both parties can express themselves rationally and diplomatically. Families are free to discuss treatment options, their loved one’s progress and prognosis, medication information, etc. And, similarly, I will argue that nurses are free to articulate and communicate their concerns if familial expectations become too demanding,

unreasonable, or unfair for the level of resources to which they have access. It is within these productive conversations where each side's goals, interests, and perspectives are described that the indispensability of dependency workers, issues of transparency, and the inevitability of dependency relations can be taken up. I will argue that in encouraging a model that focuses on open and constant communication between health care professionals and families, we are moving closer towards an ethic of care that honours dependency relations and works to provide better support for those who benefit from and those who perform labours of care.

Chapter 1 – Through Billy's Eyes

I. Introduction

When medical staff are faced with questions surrounding the degree of care, treatment, and assistance a patient requires, having discussions with that patient can often aid in providing answers for therapeutic interventions and attention. But what is to be done in those circumstances where a patient is unable to discuss her own wishes, where she is unable to explain how she is feeling, what hurts, or what she needs? In cases like this, deciphering what is in a patient's best interests is not quite so simple. In practice, medical decisions that concern patients of such limited capacities are deferred to their loved ones. While such deferrals may seem fairly straightforward in the sense that those closest to the patient are left in charge of making decisions to protect her well-being, those decisions can sometimes be heavily criticized or even discounted by the patient's nursing staff. When it comes to surrogate decisions, though much of what can be acceptably disputed among nurses and families may be caused by a lack of clarity in

surrogate decision-making standards, it is nonetheless common for families to face a tremendous amount of pressure to adopt treatment options that are favoured by their loved ones' caretakers. And, when existing disagreements in attitudes of care towards a patient often leave families and nurses feeling frustrated, communication lines between both parties become closed and relationships between family members and health care professionals become compromised. In this chapter, I shall discuss how, despite the inaccessibility of certain patients' wishes, we can manage to set up a good ethic of care that fosters the development of a positive relationship between nurses and families by validating and integrating the lives of loved ones into patient care and treatment. As much of the discrepancy that surrounds patients incapable of communicating their needs pertains to the tremendous pressure placed on the family members responsible for making medical decisions, it is important that nurses factor the existing relationships between their patients and their patients' loved ones into account. By exploring the different relationships in which the patient participates, health care professionals and the family can work towards an appropriate treatment approach that serves to protect the particularity and personhood of dependents. Moreover, in coming to define patients by more than descriptions of their illnesses, nurses are better received by others who play important roles in the lives of their patients. Recognizing the role that family plays, the challenges they face in making surrogate decisions, and the meaning patients bring to the lives of their loved ones (no matter how limited their capacities may be) will, I believe, help to create ongoing, positive interactional systems between families and nurses that promote and encourage the very possibility of a shift of emphasis in health care from the

paternalistic dominance of professionals to a respect for the individuality of each patient.

It is here that I shall explain my experiences with Billy—a patient whose limited capacities prevent his personal expression of his interests and concerns. It is through my work with Billy and the close relationship we developed that I came to grasp the importance of formulating an ethic of care that concentrates on the distinctiveness of each patient, so that, in special cases like Billy's, the development of constructive relations between nurses and families is in fact viable.

II. Billy's Life

I remember the first time I walked into Billy's hospital. There were doctors and nurses hurrying about, in- and out-patients being wheeled through or sitting in the halls, hospital equipment lining corridors, and family members scattered about in attempts to quickly find their way to their loved ones. Entering a hospital for the first time can be a rather intimidating, if not terrifying, experience. Yet despite its overwhelming aspects, there is also something intensely sad in encountering extremely ill patients as they wait to be seen by doctors, wait for treatment, and, in essence, wait to be healthy. And, no matter what your preparation or previous training, it takes a great deal of strength to cope with and get used to that feature of hospital life.

Billy lives on the fourth floor of his hospital in the Continuing Care Unit. He is lucky enough to have his own room, as most others on his floor share with two, if not three, other people. His floor is a place where those suffering from long-term and/or terminal illnesses come to stay. Most of the floor is comprised of elderly patients, with Billy being an exception as one of the few people in his forties to be part of the floor.

The facilities on Billy's floor include a common room with a television, puzzles, birds, and fish to look at, and an adjoining kitchen where snacks and food can be prepared for patients by their family members if needed. Otherwise, his floor resembles most others in the hospital: a nursing station, offices, patient rooms, seating area, etc. with hospital supplies/equipment strewn in the halls. There are various daily activities and games that are run by the nurses and physiotherapists, but none in which Billy can participate, as his condition prevents him from partaking in such festivities.

There are various senses in which I define Billy. But just as with anyone, it is difficult to come up with a description of someone's character that fully justifies or captures the essence of his being. So, let me begin by describing what I call the "medicalized" aspect of Billy. Four years ago, Billy had an accident. He slipped in the shower, hit his head, and required hospitalization for a period of two weeks. Nearing the completion of his hospital stay, Billy suffered a serious brain aneurism that necessitated several difficult surgeries. The aneurism affected Billy's motor skills, his ability to speak, and his ability to cough, breathe, and function on his own. Though the operations helped to save Billy's life, the aneurism left him completely and permanently incapacitated. He has become dependent upon medication to control his seizures, a feeding tube for eating, and a tracheotomy tube for breathing. The medication used to control his seizures makes him particularly sleepy, so Billy spends most of his time asleep, though there are days when he is quite alert and aware of his surroundings and the people around him. Billy is placed in a large reclining wheelchair four days per week (three of which I spend with him) and the rest of the time he is in a hospital bed. He is often hooked up to oxygen via

his tracheotomy tube, but he can manage to breathe on his own and away from the oxygen for short periods of time. Periodically, however, even with his oxygen, Billy requires suctioning to clear his airway since he is unable to cough or clear his throat on his own. This is a particularly stressful situation for Billy, as he cannot breathe properly when his airway becomes blocked or obstructed. Consequently, his condition necessitates constant monitoring by the nursing staff to ensure that his airway is kept clear and that he is breathing well.

While many are aware of the “medicalized” aspect of Billy, the “personal” features of Billy tend to be known primarily by those who love him and those who have been entrusted with advocating for his interests. Although Billy’s medical situation often overpowers and interferes with the other defining features of his character, Billy is a very special individual. For, despite his brain injury, he can still smile, look, listen and, at times, clutch the hands of those he recognizes. Granted Billy’s capacities are extremely limited, even despite his limitations he possesses an incredible spirit. His strength and courage shine through even on his worst days when he is having difficulty breathing as he still tries to smile and remain calm during his moments of extreme discomfort and distress. No one knows for certain the extent of Billy’s brain damage; however, most doctors believe he currently possesses mental capacities similar to those of a two-year old child. But given Billy’s reactions, I wonder sometimes if his capacities are greater than what they suggest. During my visits with him, Billy will often turn to me while I am talking to him and he will smile or frown at me at points when any other person would do the same if they were listening to what I was saying. And while I am not an expert, nor a

doctor, I think there is something to be said for the knowledge of those who spend a great deal of time with Billy. In knowing Billy the way that I now do, I have come to realize that assigning a two-year old's mentality to Billy doesn't quite fit with what I see in him. Though I cannot say for certain how much he comprehends, clearly he understands some of what goes on around him. He winces and frowns whenever his nurses suction his tracheal tube, he has been known to stick his tongue out when someone makes a joke, and he pouts when his family and friends leave him for the day. In my eyes, particularly the way Billy responds to jokes that are far above the capacities of a two-year old indicates that there is more going on in his brain than his doctors presently believe. And it is for this reason that I am strongly in favour of both an increase in the time that health care professionals spend with long-term care patients as well as an increase in the time they spend talking with the families of those patients. Perhaps if Billy's doctors were made aware of Billy's reactions or if they were able to witness them for themselves, they wouldn't have been so quick as to assign the level of mental capacity to Billy that they selected in the first place. But as I have witnessed at Billy's hospital, when his doctor only makes his rounds on the floor once per week and only makes an effort to see Billy when Billy's medical condition has deteriorated, the chances for his doctor to witness the reactions that Billy often displays are few and far between.

To most, Billy's reactions may not seem extraordinary, but they are major accomplishments in the eyes of those who love him. They indicate signs of life beyond his medical condition—signs of who he used to be—and they offer hope for his family that one day, somehow, Billy will become well again.

I met Billy a little over a year and a half ago and immediately became drawn to and touched by the remarkable spirit and determination he displays. My role in Billy's life is twofold: (1) act as his caretaker; and (2) act as his mediator between his nurses and his family. While Billy is looked after primarily by his nurses, his family relies on me to ensure that certain smaller aspects of his care are met. These duties include making sure he is never left unkempt, that his airway is kept clear throughout our visits together, and that his limbs are stretched and exercised regularly. In addition, it is my responsibility to see that the concerns of his family members are expressed to his nurses while being careful to manage their requests so that his family is not asking for care that is unrealistic for his nurses to provide. This last feature of my work can, at times, be particularly challenging when it comes to mediating requests for care and keeping both family members and nurses happy with Billy's care. On both fronts, I believe much of the frustration and aggravation I have come into contact with pertains to questions surrounding who is in the proper position to determine what is right for Billy. As I shall discuss in the next two sections, improving the care of Billy and others in long-term care facilities is dependent on creating respect for patients as persons and the development of a surrogate decision-making standard for long-term care patients that focuses on both family and patient interests.

III. Personhood and the Particularity of Patient Relationships

Let me begin by describing a 'typical' (though often changing) day with Billy. When I arrive on his floor, despite my calling ahead to ask that the nurses have him ready and waiting at the elevator so that I may bring him downstairs to the lobby for a change of

pace, Billy is often left in his room and not prepared to go out. Most days, I find Billy in his room watching television, with his feeding tube connected and his oxygen attached. While this may not seem like that much of an imposition, some members of Billy's family can only go to the hospital on their lunch hour and, when nurses are difficult to track down on his floor, it can be particularly frustrating for his family to spend most of their time at the hospital searching for someone to unhook Billy's feeding tube, take off his oxygen, and suction his airway so that he can then go off the floor to be with his family. Their frustration often carries over into heated discussions with his nurses about the lack of attention Billy receives, as he requires constant monitoring to ensure that his airway remains unobstructed and that he is breathing properly. Their point of concern is that time and again when it is impossible to find a nurse to help take Billy away from his medications, off of his oxygen, and to get him suctioned, leaving Billy alone for such long periods when his family or I are not around to monitor his condition could potentially lead to a situation where his airway could become blocked and, since he cannot page a nurse on his own, he would then choke to death. His family's concerns, while expressed at times in not the most pleasant manner, do carry with them an important message regarding the length of time Billy is to be left alone, a message that one might expect his nurses to take into greater consideration, particularly when Billy cannot ask for assistance if he were to run into respiratory difficulty. Granted it is unfair for his family to ask that a nurse be assigned exclusively to Billy as this, of course, is entirely unfeasible given governmental cutbacks and present nursing shortages; but, in fact, such an extreme measure is not at all what his family is requesting. It seems to me,

after much discussion with his family, what I understand them to be asking is that Billy's care be structured differently so that he is somehow factored at regular intervals into the routine of the nurse to whom he is assigned each day. For instance, if his nurse was able to check his airway every forty-five minutes instead of attending to Billy only when he can be heard gasping for air, his family would be much more comfortable knowing that his nurses are being proactive towards Billy instead of being purely reactive to his moments of pain and distress. But these suggestions, while good, have yet to be presented to his nurses because Billy's nurses simply do not have the time to meet with his family to discuss alternative care options. When they are assigned approximately seven patients per shift, taking time out of their work to meet with families is simply impossible. So, while Billy's family is right in claiming that the care Billy presently receives is inadequate, unless his nurses gain access to additional staff so that the number of patients assigned to each nurse can be diminished, even if families could sit and discuss issues of care, their requests cannot be met without additional staffing resources. As I shall suggest in the next chapter, more must be done in order to encourage others to participate in care work so that nurses do not experience burnout or dissatisfaction in their career. And, if families are to make reasonable requests, once additional resources become available to nurses, opportunities must be set up between nurses and families wherein families can speak to one another regarding suggestions for care. That said, of course, there are many other issues that Billy's family often wants to present to the nursing staff that I do recognize as somewhat excessive. These requests include insisting that his hair is combed a certain way or that he wear a specific shirt or sweater.⁴ But I

stress that when it comes to their worries regarding Billy's health, I do believe something must be done so that nurses are able to listen—in some capacity—and take the uneasiness of the family into account.

At present, it is very difficult to reach decisions that satisfy both Billy's family and his nurses, and I have often been part of conversations where each side is unhappy with the other's actions or choice of conduct. Billy's family is regularly accused of making demands that are unnecessary and, similarly, his nurses are often accused of neglecting his needs and failing to remember that despite his medical condition, he is still a real person. Let me begin by addressing the latter of these two concerns—that is, how Billy and those in possession of his same limited capacities often become categorized and referred to by what Theris Touhy identifies in her article, "Dementia, Personhood, and Nursing: Learning from a Nursing Situation", as "empty shells" or "ex-people" (Touhy, 44). Billy is often treated by his nurses as though he is a "vegetable" based on the assumption that since he cannot communicate, he is unable to overhear conversations or understand their content. It is not uncommon to walk into Billy's room and witness, as he is being attended to, an entire conversation between his nurses that pertains exclusively to their own personal affairs. In essence, apart from the physical attention it takes to dress, change, or suction Billy, his nurses express very little interest in his character and his presence since he cannot respond or participate verbally in their conversations like many other patients on his floor are able to do. As a result, Billy's invisibility and isolation reinforces the mistaken idea that he no longer exists outside of his medical needs—making the idea that he was once a person who could socially interact easily forgotten.

Though Billy's quality of life may not be what it was before, one cannot deny that he is a person, despite all that he has endured throughout the last four years of his life. But when his name is no longer attached to his existence, when he becomes identified by his caretakers as simply "the patient in room 410" or described as a "vegetable", it becomes easy to understand why his nursing team repeatedly alleges that his selfhood has, in fact, been lost. I recall one occasion in particular when one of Billy's nurses approached me and informed me that his family ought not to hold any false sense of hope for Billy. She stressed that I work with his family to help them to understand that Billy would never become well again and that it would be best for them to work with the nursing staff to accept that the Billy his family once knew was gone for good. Of course, admittedly it is important to be realistic about illness and, undeniably, there is truth in what this particular nurse said about Billy never returning to his full capacities—especially given the extent of his brain injuries; but to suggest that he no longer retains any aspect of who he used to be, I believe, robs Billy and those close to him of the meaningful relationships they continue to maintain throughout the course of his medical complications. And, further, when his doctors are unsure of Billy's mental state, it seems unfair to assume that his inability to respond in any sort of significant capacity suggests that he is then without a mind or not to be considered a *real* person.

As I see it, personhood is reflected in a series of attributes, and the ability to communicate needn't be such a defining feature of what it takes to possess it. As Kittay writes in reference to her daughter Sesha—a young woman suffering from severe mental retardation and cerebral palsy,

“She is fully human, not a vegetable. Given the scope and breadth of human possibilities and capacities, she occupies a limited spectrum, but she inhabits it fully because she has the most important faculties of all. The capacities for love and for happiness.” (Kittay, 151-152)

Clearly there ought to be more to personhood than what we have traditionally accepted it to be. In fact, several authors (Bahr, 1992; Kitwood, 1997; Kitwood & Bredin, 1992) define personhood as exhibited in a vast array of attributes, including: “wholeness, peacefulness, joyfulness, contentment, self-worth, self-esteem, purposefulness, and spirituality” (Touhy, 44). Touhy recommends that in order to preserve the personhood of patients living with limited capacities, nurses ought to practice a *nursing as caring* approach: wherein nurses actively engage with their patients and come to know them as persons instead of responding strictly to communication, behavioural, and functional deficits (Touhy, 45). According to Touhy, it is a dire mistake to treat patients like Billy simply from a biomedical perspective; instead, she believes it is far more productive to stand in caring relationships to one another as entire persons, without neglecting or disregarding aspects of another’s being—no matter how compromised a patient’s mental capacities may be (Touhy, 44). For, as she describes, a caring relationship “.. is the intimate, personal knowing of the person behind the disease and the creation of relationships and environments of care that support, validate, and celebrate the other as someone of value and worth” (Touhy, 44). The personal knowing that Touhy refers to, as I see it in a case such as Billy’s, is entirely dependent upon one critical factor that is ubiquitous in human society: recognizing that we are all part of relationships and that the roles we play in our relationships help to shape and make us who we are.

What I am suggesting, therefore, is that instead of describing Billy as ‘vegetative’—a description that I feel denies one’s self-worth, dignity, and honour—we describe Billy in ways that validate who he is according to the relationships he has formed in his life. For instance, Billy is a brother, a son, an uncle, and a treasured friend to a very large group of people. It seems to me that if we were to celebrate the roles he plays in these relationships—the contributions he has made, the bonds he has formed—then it would be possible to have an entirely different picture of who Billy is; a picture that could then possibly stand apart from his medical difficulties.

On the other hand, if nurses are to aid in restoring, preserving, and maintaining the lives of their patients, why must they take into account the relationships their patients participate in? In other words, why is it important to place emphasis on the recognition of patient personhood? As I see it, developing a good understanding and recognition of the personhood of patients like Billy will help to bring nurses and families closer to a consensual understanding of what may be in these patients’ best interests. Of course, this isn’t to say that when it comes to all aspects of care a consensus could be reached by both parties on every occasion; but, at the very least, expressing interest in the relationships of each patient can, in turn, help to strengthen the relationships between nurses, their patients, and their patients’ loved ones. In Billy’s case, his family is far more receptive, relaxed, and responsive with the few nurses who talk to Billy, know his family members names, and are familiar with the relationships his loved ones have with him. In addition, his family is far more trusting and willing to accept the suggested courses of treatment for

Billy that these nurses recommend versus the suggestions made by nurses who view Billy strictly in terms of his illness.

IV. Adopting an Appropriate Surrogate Decision-Making Standard For Long-Term Care Patients

Claiming that nurses ought to strive to get to know their patients better may at first seem peculiar when, ultimately, those who are closest to the patient are the ones who are responsible for making treatment decisions. Encouraging nurses to respect the personhood of their patients wherein nurses establish relationships with their patient and their patients' families seems slightly futile when surrogate decision-making in cases of long-term care are, for the most part, left up to families. In my experience, however, nurses do not easily defer matters of care to the families. In fact, nurses tend to voice their opinions quite strongly when it comes to care or treatment decisions for their patients even in spite of arguments that the patient's family might make for the family knowing their loved one the best. Admittedly, it is difficult to make the case that families ought to have the right to exclusively decide the appropriateness of various treatment options when, for most long-term care patients, the implications of their decisions will surely impact that patient's nurses. Consider the following case of Steven Dawson:

"Stephen was a seven-year-old boy who had a combination of physical and intellectual disabilities. His parents had placed him in a facility when he was two. He had hydrocephaly as a consequence of meningitis which he contracted as a baby. In 1983 the shunt which had been installed to drain cerebrospinal fluid from his head became blocked. Fluid was building up inside his cranium, causing great discomfort and posing a threat to his life" (Endicott, [online]).

Stephen's parents fought not to have the shunt 'revised' as they claimed that due to quality-of-life considerations it was best for Stephen to die (Kluge, 148). His caretakers, however, who saw him on daily basis and believed that he enjoyed life, were unsatisfied with their decision, intervened and the matter came to trial in provincial court. Though the court decided in favour of the parents, on appeal to the British Columbia Supreme Court, the decision was reversed, in part on the grounds that a congenitally incompetent person does not lose the rights to health care normally enjoyed by other persons simply in virtue of his or her incompetence (Kluge, 149). Thus, Stephen was allowed to receive treatment and continues to live today (Kluge, *ibid*). Evidently, then, there is something to be said for the epistemic perspective and the advocacy of nurses who are responsible for all aspects of care for long-term patients. For when a nurse is heavily involved in the day-to-day care of a patient, it can be quite easy for her to feel that her opinions ought to matter and her perspective on the care of that patient ought to be included in the deliberations of the family. And why shouldn't it be included? After all, when long-term patients spend most of their time without their families and the nursing staff is responsible for their well-being around the clock, understandably nurses begin to perceive their perspective as privileged or most knowledgeable (whether they choose to respect the patient as a person or not) than families when it comes to the care of their long-term patients.

It is here, however, that I think we run into difficulty. In long-term care situations, when nurses or families view their perspectives as privileged and create hierarchical distinctions between each other's role in the life of the patient and the care he or she

needs, animosity between both sides is encouraged and this does little to promote productive communication between them. As a result, surrogate decision-makers are often interrogated about the decisions they make and can, at times, face coercion by the nursing staff to select a different option—one that they, as health care professionals, deem to be more suitable. And, insofar as nurses feel justified in pressuring families to accept certain courses of treatment, their actions are in conflict with protocol set up by clinicians for health care providers. According to Neil Lazar, M.D. in his article, “Bioethics for Clinicians”,

“The role of the health care professional is to facilitate the process of substitute decision-making by providing information that will enable the substitute to make an informed choice on the patient's behalf. Health care professionals should guide the substitute to consider the patient's previously expressed wishes, values and beliefs, or best interests (in this order). When it is apparent that the substitute is making a choice that is significantly different from what the patient might have chosen, health care providers find themselves in a difficult situation and should seek advice from colleagues, ethics committees and legal counsel” (Lazar, 1436).

In Billy's case, many of the decisions critiqued by his nurses could hardly be considered *drastically* different from what Billy would have chosen because it is impossible to know for certain what Billy would have wanted when so many of the decisions made regarding his care are simply far too specific. Even had he been given the chance to express his values or wishes before he became ill, the conflicts I have witnessed between Billy's nurses and his family do not pertain to life-threatening decisions. Rather, they are arguments that relate to the sort of care he receives daily. The following is an example of

the conflict I have encountered as a result of Billy's nurses' and his family's care assessments.

Lately, during my visits to the hospital, I have noticed, on several occasions, Billy's positioning and posture in his wheelchair to be quite poor. He often slumps to one side or slouches down with his head bent towards his chest. This is a somewhat precarious position for Billy as sitting in such a manner risks cutting off the air he receives through his tracheotomy tube. As a result, his nurses have begun to pressure his family in the hopes that they will opt for a different chair; something that offers better support for Billy and keeps his head upright. Yet, not only is his family reluctant to purchase the chair when the one in which he now continues to sit has managed to suffice in the past but, also, acquiring the chair will place a tremendous financial burden upon Billy's family. Moreover, it seems that when the nurses take the time to position him in the chair properly, he sits quite well in it without any slippage. In a case such as this, whilst the decision ultimately resides with the family (as a new chair can only be purchased at a cost to Billy's relatives), their decision does not seem to prevent his nurses from pushing the family to consider this expenditure. This pressure has since intensified into blatant disagreement between both parties which, in turn, has led to the breaking down of any salvageable, non-confrontational communication between Billy's family and his nurses.

According to Section 27 of the Health Care Consent Act for Ontario:

If consent to a treatment is refused on an incapable person's behalf by his or her substitute decision-maker, the treatment may be administered

despite the refusal if, in the opinion of the health practitioner proposing the treatment,

- (a) there is an emergency; and
- (b) the substitute decision-maker did not comply with section 21.

where Section 21 pertains to the principles a surrogate must take into account before giving or refusing consent. These principles as outlined in the Health Care Consent Act include: respecting any previous wishes, values, or beliefs of the patient; and whether the treatment will improve, prevent, or reduce deterioration to the patient's condition or well-being. Section 27, in granting health care practitioners (where members of the College of Nurses of Ontario are included in the Act's definition of "health practitioner") the authority to overrule decisions of family members, seems highly contentious given the vagueness of Section 21. When dealing with matters where a patient's wishes are unknown, where specifications have not been made for care prior to becoming debilitated by a medical condition, how ought a nurse to assess from an impartial perspective whether a family's selected treatment will, in fact, preserve the well-being of that patient? For just as families are expected to not incorporate their own values and interests into decisions that concern the well-being of their loved ones, on account of Section 27, nurses are also expected to remain unbiased in their evaluations of the health care decisions families select. But, it seems that if we are to give all health care practitioners the right to overrule the requests of family members, even in light of the specification that such rulings are to only take place in an emergency, there is a risk of a slippery slope wherein what counts as acceptable circumstances in which decisions can be overridden by health care agents transcends what Section 27 set out to sanction.

Consider once more the case of Billy's family and the conflict they continually find themselves in with his nurses over Billy's wheelchair. While his family's decision not to make the purchase is not *actually* overridden by his nurses, Section 27 does give his nurses the capacity to do so despite the financial burden a new chair would place upon Billy's family. It seems to me that in upholding Section 27, where costs could very well be expected to be incurred by families who strongly opposed the treatment administered, tensions between nurses and families will continue to escalate. Of course, it mainly comes back to resources. Surely it would seem that if the hospital was willing to incur the cost of a new chair, his family might be more open to Billy's nurses' suggestions, right? But having access to additional support or greater funding (the present scarcity of which drives much of the tension between nurses and families) is not all that is at issue. Returning to Billy's case, the hospital did look into having the physiotherapy department cover the cost of the chair. During that time, his family was shown a series of new chairs that they could choose from. Upon looking at the chairs, however, his family still felt that his current chair was best designed for Billy because it offered much more padding in its headrest than the others, and they remained set in their decision. So it seems that even in cases where additional resources are available, what drives the tension between families and nurses may not be entirely related to limited resources. In fact, I claim that, partly, the tension nurses and families experience over long-term care decisions comes from a lack of clarity in surrogate decision-making standards that we presently practice.

According to O’Hara and Neutel in “A Shadow of Doubt: Ethical Issues in the Use of Surrogate Consent in Research”, there are three types of decision-making that proxies use:

- (a) Considering what the [patient] might have preferred,
- (b) Looking out for the best interests of the [patient], and
- (c) Serving the agenda of the surrogate⁵

In the case of (a), otherwise known as the *substituted judgment standard*, the surrogate attempts to make medical decisions for the patient based on their knowledge of the patient’s past behaviour, preferences, attitudes, interests, and opinions. While this approach is respectful of patient autonomy, insofar as it attempts to match up with the values the patient held prior to their disability, if a patient has always been severely disabled or the values of a patient are unknown⁶, this approach is lacking in its applicability to long-term care situations. For example, in Billy’s case, the onset of his disability was immediate; he did not have time to write down or explicitly identify the sorts of treatment he would want if he were to become incompetent. And, as O’Hara and Neutel indicate, when the substituted judgment standard is employed and patient values are delineated prior to the onset of illness, when patients regain competency later, there is poor correlation between “what people say they would do under certain circumstances and what they actually do when those circumstances arrive” (O’Hara & Neutel, 9).

In the *best interests standard*, (b), proxies try to be objective in determining what best promotes the well-being of the patient. The difficulty with this approach, however, is that it is not easy for the surrogate to avoid employing her own values, standards, and expectations when the resulting decision will undoubtedly have an effect on the

surrogate's life.⁷ As a result, the *best interest standard* risks being parentalistic⁸ and may not be in line with what would be good for the patient. It is hard for a surrogate to separate out what she believes to be in the patient's best interest from what the surrogate wants to see happen, particularly when she too will likely be affected by the decision. The best interest standard is risky because patient interests can become easily replaced with those of the surrogate—whether intentionally or not.

Though (a) and (b) offer norms for surrogate decision-making, (c) involves the “primary interest of the care and well-being of the [patient being] unduly influenced by a secondary interest, such as financial gain by the surrogate” (O’Hara & Neutel, 9). Despite its unacceptability, (c) depicts how people sometimes behave when entrusted with the interests of another. Evidently, we must find an approach that can offer greater guidance for surrogate decision makers; one that recognizes the ethical legitimacy of taking into account the interests of family members in the decision and makes their role transparent rather than hidden.

Upon examining (a), (b), and (c), it seems we have fallen short of decision-making guidelines that can aid in the resolution of conflict between nurses and families while, at the same time, help us to improve the care that patients are currently receiving. My argument is that instead of assigning surrogate decision-making status by a process of ranking individuals based upon who knows the patient better or who provides the most care, we instead implement a standard that regards the interests of all those involved in the patient's hospital life as relevant and deserving of consideration.

To this end, I think we are far better off implementing a surrogate decision-making process that incorporates, in some capacity, the interests of participants in the patient's care into medical decisions. Hence, as an alternative I propose the *collaborative standard*:

- (d) In matters of surrogate decisions in long-term care, (i) the interests of the patient, her family, and the nursing staff are all to be considered morally relevant and (ii) medical and non-medical decisions for the patient must result from the collaboration of all persons involved in her care.

I do wish to stipulate that I am using “family” here to refer roughly to “those who are close to the patient” (in addition to relatives, this can include close friends, companions, guardians, etc.). In special cases of patients without “family”, a patient advocate ought to be appointed to represent the interests of the patient. My reasoning for arriving at such an inclusive standard stems from my belief that while we are all deserving of good long-term care, we cannot expect that in promoting the quality of life of long-term patients, we are morally justified in compromising the quality of life of those involved in providing long-term patient care. For as Hardwig explains, “It is one thing to claim that the ill deserve special consideration; it is quite another to maintain that they deserve *exclusive...consideration*” (emphasis mine, Hardwig, 105). In including the interests of those involved in patient care, surely this ought not to mean that the interests of the patient are neglected or omitted from care considerations. Chances are that even with taking all relevant interests into account, those of the patient will be well protected since some interests likely to be weightier than the rest (since they concern matters of life, death, reductions of pain, etc.). In this sense, the interests of all participants are brought

to the table and accommodated as best as possible. I think that we are much better off if we adhere to a more inclusive surrogate decision-making standard, where we attempt to take all related interests into account and balance the interests of the patient with the level of resources and support available to adequately respond to those interests. When families ask nurses to provide greater care for patients than nurses can manage, families become frustrated when their requests cannot be met. And though I shall argue in the following chapter that support for nurses must be increased and the needs of nurses taken up as a social responsibility, revisions to our present “individualistic medical ethics” are definitely in order. Treatment decisions affect more than one, and hence, should not be left entirely up to the devices of the family when, in long-term care, nurses are expected to be chiefly responsible for actualizing that care. Further, as M. Benjamin and J. Curtis suggest in *Ethics in Nursing*,

“If more collaborative relationships can be established, several positive results can be expected: (1) an increased likelihood that the parties will reach a well-grounded and mutually satisfactory decision; (2) an appreciation of the ethical dilemmas nurses face in being ‘caught in the middle’⁹; and (3) lower medical care costs because of reduced ‘burnout’ among nurses.” (Benjamin and Curtis, 102)

Instituting more “democratic procedures”, wherein all parties are able to express their points of view, avoids the risk of nurses and families participating in parentalistic coercion—where either group may be forced into accepting medical decisions they may strongly oppose. And, while coercion may have the best interest of the patient at heart, according to Benjamin and Curtis,

“To disregard or give only perfunctory consideration to the values and life plans of others is to show contempt for them as persons. It is to regard

them as mere objects or things rather than one's equal as persons, *even if one's aim is to benefit them or protect them from harm.*" (Benjamin & Curtis, 54)

Hence, despite its aim to ensure that "the patients receive the interventions that best promote their health and well-being" (Emanuel & Emanuel, 39), it is easily recognizable that setting up surrogate decision-making practices that are exclusive or privileging of one party's interests over another is undesirable when all members are actively involved in the care of the patient. Adopting the *collaborative* standard where family and nurse communication is a prerequisite of all long-term care patient decisions, encourages, I believe, better care for patients and speaks to the impracticality in long-term care of making individualistic decisions.

V. Collaboration

As mentioned at the outset of this chapter, when faced with medical decisions that concern patients unable to express their needs, wishes, or individual interests, it can be especially taxing to come up with an ethic of care that serves patients, without compromising the lives of those responsible for their care. In such cases, as conflicting opinions arise between nurses and families over what constitutes the best possible medical treatment or procedure for the patient, it appears that two things are essential if we are to achieve positive results in such complex health care situations: (1) patients must be treated as persons—no matter how limited their capacities; and (2) the collaborative standard must be put into practice so that nurses and families are able to "deliberate in a spirit of mutual respect" where each side reflects upon courses of action as suggested by one another (Benjamin and Curtis, 104).

As Billy's identity is constituted by the close relationships in which he participates, it seems that one way to get at the best course of action for his needs is to uncover what best suits the values and principles his relationships have set up for him. As a result, promoting mutual deliberation and encouraging collaborative decision-making—wherein nurses and families are able to share their positions on treatment in a non-confrontational manner and the personhood of the patient is recognized—can assist in the development of a much healthier hospital experience for all those involved.

But mutual deliberation and collaborative decision-making are not all that is needed in order to get a project for improving care for long-term patients off the ground. Returning to the impasse over Billy's wheelchair, even if deliberative efforts help his nurses to comprehend that financial constraints are what prevent his family from purchasing a new chair, deciding against a chair is still dangerous for Billy unless his nurses seat him in his wheelchair properly. But when finding extra equipment and hands to lift Billy into his chair has become a challenge for nurses since they are assigned more patients in a shift than they can manage, the problem cannot just be resolved by negotiating with current participants in Billy's care. For even if it is decided that Billy will remain in the wheelchair his family already owns, without additional support and assistance, his health will become compromised because he will continue to be placed poorly into his chair. The social reality of nursing practice must first be addressed in order for progress to be possible in the dilemma over the wheelchair.

While there are differences between contractual and non-contractual dependency

work, both kinds of workers can be said to bear obligations to their charges not entirely of their own making. Whereas parental or familial ties can dictate the responsibilities that women have to those who depend upon them, those who engage in paid health care work can also find themselves in situations where the expectations their health system places upon them are often far too demanding and draining to their roles as health care professionals. Nursing, insofar as it constitutes the largest element of female paid care and makes up a significant proportion of national labour forces (Carpenter, 95), is one of these areas of health care where individuals receive very little recognition, compensation, and relief from the work that they perform. Not only do the contributions nurses make to health care tend to go unnoticed by others occupying higher positions within health service hierarchies, but their invisibility also tends to get carried over into social patterns of subordination. As Mick Carpenter argues in his article, “The subordination of nurses in health care”, the lack of support nurses cope with is, in part, a function of wider divisions of social power (Carpenter, 97).

Despite the alleged gender-neutrality of caring labour, women have occupied the overwhelming majority of caretaker positions. In a society where the roles of breadwinners and dependency workers have been defined by gender, women have predominantly been expected to carry the weight of dependency work, while men, in return, protect them from other men and provide their women with economic resources (Kittay, 41). And, while it may appear that women who take up paid caretaking have entered into the public realm as free and independent equals like their male counterparts,

in reality most have done so only at a further cost to their own interests, needs, and concerns. In this chapter, I shall discuss the significance of societal expectations on women and how these demands mirror or, at the very least, infiltrate health care policies and practices. Insofar as dependency labour depletes the selves of nurses, I claim next that we must recognize, restore, and find ways to meet their needs as individuals if they are to be expected to maintain and provide good care for the sort of patient upon whom I focus: someone who is unable to express his/her needs and concerns. Finally, I offer Kittay's notion of a connection-based equality, a position that recognizes that nurses are both essential and vulnerable, and suggest that starting out with the idea of all of us as some mother's child will help to close the gap between nurses and their charges and, in addition, encourage greater social assistance for dependency workers.

I. Social and Health Care Approaches to Dependency Workers

Despite feminist efforts to eliminate oppression surrounding one's social location, cultural circumstances, and gender, there is no denying that certain oppressive societal factors have managed to filter into health care practices. In fact, as Diana Meyers claims, "Little progress has been made in uncoupling caregiving from gender" (Meyers, 19). Evidently, someone must care for dependents and, since women have traditionally been assigned the care of children, elderly parents, home and hospital care, so too has nursing followed suit in its assignment of women to further dependency relationships outside of the home. While it can be argued that women may now exercise their autonomy and freely choose whether or not they wish to become nurses; once situated within the profession, it becomes rather difficult for the voices of nurses to be heard. As Mick

Carpenter writes, “various advances in nursing are not entirely autonomous, but are critically and significantly affected by existent power imbalances in the wider society, which then become embodied in the health care system” (Carpenter, 96). For instance, just as women in the past were expected to respect the authority of their husbands when it came to decisions regarding their family, so too are nurses currently expected to adhere to and abide by decisions made by doctors and their supervisors. Health care systems mirror familial expectations insofar as both involve issues of power within systems of dependence and both poorly compensate or acknowledge women for the work that they perform. Accordingly, it is not easy for nurses to express their opinions, points of view, or to be taken seriously particularly when they are being reduced and grouped together as worthy only of a “singular nursing subjectivity” (Herdman, 3). As Carpenter explains, “team work may be the order of the day, but the doctor is still the leader of the team” (Carpenter, 104). So, it seems the increased control nurses have over their work is largely fictional. And this, as I see it, raises an important issue surrounding development in nursing.

An objector might argue that nurses today have come a long way in terms of the equipment, facilities, and scientific knowledge they now have access to; but this hardly seems enough to eliminate or “erode the foundations of the legitimacy of the power [that is] exercised over nurses” (Carpenter, 106). If these supposed developments have not been a response to the values and desires of nurses concerning their working environment, they can only be seen as further examples of the role of the dominant elite

in health care and responses to broader social trends (e.g. desire to keep costs down, naïve belief in technology)

According to Elizabeth A. Herdman in “The illusion of progress in nursing”, when we make claims of progress or development, generally speaking, this involves the implication of improvement (Herdman, p. 7). But, as Herdman suggests, we must consider whether or not the changes in nursing do, in fact, make things better and, if so, better for whom (Herdman, p. 7)? Nursing shortages that stem from governmental cutbacks have resulted in the substitution of unskilled and untrained workers in place of qualified and experienced Registered Nurses. UAPs (Unlicensed Assistive Personnel) and health care assistants are now performing various nursing functions (i.e., suctioning, stapling and suturing wounds, CPR, inserting intravenous needles, etc.) with minimal supervision or instruction (Herdman, p. 7). And, insofar as health care systems opt for cheaper nursing labour¹⁰ and patient safety becomes compromised, ‘progress’ can only refer to technological advances and the reduction of quantitative economic costs.

Regrettably, however, claims to progress remain prevalent within the orthodoxy of nursing and much of this discourse has emerged out of an overwhelming desire to professionalize nursing (Herdman, 3). As nursing training has made the transition from a college program to a university degree, there is a dominant assumption that only higher levels of education will strengthen the power and status of nursing and, at the same time, ensure that nurses are able to keep up with the technological advances of their profession. While this transition was sought after in order to raise the prestige of nursing and

encourage its recognition in the public sphere, the move hardly improved conditions for female dependency workers when, according to Sue Forsyth,

Professionalization strategies used by nursing are both inapplicable and problematic for nursing. [T]he strategies of professionalization have enabled male nurses to gain advantages over female nurses because professionalization is a ‘masculine model’ which makes it easier for men to meet the demands of a profession (1994, 132).

Surely, on the surface it would seem that more strenuous educational programs might legitimate and encourage the recognition of nursing as a profession; but in actuality, claiming professionalism as progressive for nursing does nothing but conceal the reality of those features of paid dependency work where “a diminution of independence, increasing stratification and division of labour” continue to exist (Wagner, 1980, 272).

In separating out nurses into categories based upon their academic experiences and credentials, the self-worth of nurses becomes even more compromised as nurses become ranked according to their educational levels rather than focusing on providing support for one another. It seems to me that encouraging the authority of those caretakers in possession of university diplomas over those with college certificates only serves to reiterate power imbalances within the health system, give the façade of progress, and create negative self-comparisons among nurses. As I shall argue in section III, attention must be paid to the needs of the paid dependency worker, wherein she is recognized for more than simply her schooling, but also as an individual in need of the assistance and support of her colleagues, supervisors, and the rest of society.

II. Nurses as Transparent Selves

When it comes to the issue of vulnerability within caring relationships, the patient's vulnerability is often, understandably, foregrounded and the vulnerability of caregivers overlooked. While I am not suggesting a 'vulnerability comparison', I do believe it is important to consider both sides of the relationship if nurses are to be expected to provide good care for their patients. As I shall argue further in the next section, a nurse operates with tremendous expectations upon her shoulders. The intensive demands of providing care for her charges necessitates that, at times, she set her own needs and interests aside for the sake of meeting the care requirements of others. Of course, I am not suggesting that we change this feature of the nurse/patient relationship because if we were to abandon or ignore the needs of dependents, then the vulnerability of patients would be exploited and their right to good health care violated. Instead, my purpose for bringing the vulnerability of nurses to light is purely to demonstrate the danger to a caretaker's identity when she engages in dependency work, notwithstanding her choosing the work and being paid for it.

As Elisabeth Gedge describes in "Caretaking Work and Transparent Selves", threats to the practical identities of caretakers is built into the work itself (Gedge, Unpublished paper, presented at the Canadian Bioethics Society Conference, Calgary, Alberta, October 2004). Nurses have an outright obligation to respond to their patients' basic needs and care interests. They must be what Eva Feder Kittay describes as "transparent selves"—selves that acknowledge and meet the needs of others before acknowledging and meeting their own (Kittay, 51). The incorporation of this feature into nursing practice, however, is not without difficulty when it means that patient claims of

attention must displace any attention nurses pay to themselves. And, while encouraging that the transparency of selves become characteristic of all nurses so that patients receive the best care possible, we must also find a way to respond to the vulnerability that this places upon nurses—especially since nurses are expected not to allow their own needs to obscure or affect the care of their charges in any manner whatsoever.

Maintaining nurse transparency is fundamental in dependency relationships where patients are unable to make requests for care. In these cases, I claim that patients *must* have access to the attention of their caretaker so that their condition is continually monitored and their health protected. This point becomes apparent when we stop to consider one of the reasons that Kittay offers in defense of transparency in dependency relationships:

“An interference with the transparency of self can have dire consequences. An infant’s caregiver who is more attuned to her own needs than to those of her charge can fail to notice or can disregard important, even life-threatening needs. It is neither capricious nor misogynist nor disrespectful of individual rights when we insist that individuals who mother infants or young children defer their own desires, and even needs, to meet those of their dependent child” (Kittay, 52).

It is this very reasoning that I believe ought to apply in situations of extreme dependence, where patients are entirely dependent upon the nursing staff. Just as infants are unable to express their own concerns, one can argue analogously that patients in possession of similar characteristics require the same constant attention and care as children. Of course, we must be careful that in drawing comparisons between these two relationships of dependence we do not infantilize those patients who, despite their present state of incompetence, have been and are still persons with unique characteristics and life

experiences worthy of our protection. In addition, deciphering the needs of one's charge (a feature of acting as a transparent self) requires that a nurse establish special relations that protect the particularity of the patient which further helps to prevent the treatment of adult patients as infants.

The moral claims in caring relationships are different from those made within relationships among equally situated persons, since such individuals can advocate for themselves. But nurses, even in light of their choice to become paid dependency workers, carry a moral responsibility to their patients that can often trump the moral responsibility they have to themselves. In my experiences as a volunteer at a local hospital, when there are only five or six nurses assigned to a floor of fifty patients, the nursing staff can find it very difficult to maintain the moral obligations they have to their charges without cutting into their scheduled (and well-deserved) periods of rest and relief. Being responsible for the welfare and health of those unable to reciprocate that responsibility towards their caretaker can leave a nurse feeling fully depleted of her resources and energy. And, when shifts run for an average of twelve hours in length, there is little energy left for one to care for herself at the end of her day at the hospital. Evidently, opting into nursing can be highly demanding and exhausting for those who choose to take on roles in paid caretaking. But, as it stands, serving the interests of another prior to serving one's own can leave nurses in positions where they neglect their own needs, especially when support for caretakers within health care and society is minimal or unavailable.

Having said all of this, however, someone might argue that, since the work is voluntarily chosen, if the conditions are inadequate nurses can quit and seek employment elsewhere. So, is it fair to propose ‘special’ recognition and support for nurses when their vulnerability is seemingly temporary or self-induced? But just as social expectations shape the workplace and limit the resources available to nurses, social viewpoints also shape our choices and the options to which women have access. When gendered expectations funnel women into care work and when they cannot morally or psychologically opt out of it due to its indispensability, being a ‘relational’ or ‘giving’ self generates patient loyalties and expectations that are not easily shrugged off. In acting as a transparent self and mediating the needs of others before one’s own, the moral demands placed upon nurses can hardly be regarded as voluntary or optional. And while it may be possible to assert that nursing is contractual and women can quit whenever they choose, once special relations and ties are set up between caretakers and their charges, it becomes especially difficult for a nurse to walk away from the moral obligations she assumed for her patients—particularly when, as Kittay claims, “the fulfillment of those obligations is now her responsibility and hers uniquely” (Kittay, 67). And when, as she goes on to argue, “the lack of social supports for the disabled and those who care for dependents constitute a denial of our inherent vulnerability to disability” (Kittay, 174), exit options for nurses are limited, and they must face the guilt of knowing that if they opt out of the work, then it is possible that no one else may be willing to take it up in their place or that someone else would have to experience the same poor working conditions and weighty obligations that they already do.

Furthermore, it is often very challenging (in nursing and in all areas of work) to prevent the difficulties one faces at work from infiltrating the other parts of one's life. While I am not suggesting that other jobs are not as demanding or as grueling as nursing, I strongly believe that there are certain aspects of acting transparently that can leave nurses feeling devoid of their visibility and individual personhood. Spending one's entire day focused on the needs of others without any sort of reciprocity for her own well-being can be utterly exhausting, and it is naïve to argue that those feelings do not carry over in some capacity into a nurse's personal life. In most cases, women are never free from dependency relationships. So, even though nurses may finish a shift at 7 p.m., many have families that they must then go home to and perform a series of tasks that they have already provided for their patients throughout the course of their shift. Laundry must be done, beds changed, children bathed, dinners cooked, etc. and so it seems hardly fair to suggest that transparency of the nursing self somehow disappears once a nurse goes home for the day since, at that time, many nurses have an entire new shift of dependency work to begin.

While instrumental rewards such as pay conditions and the prospect of promotion are needed if nursing is to gain recognition and be viewed as indispensable work, having access to financial resources hardly provides enough social support to enable nurses to go out in the world and function just the same as those who do not participate in relationships of dependence. For just as Gedge describes in her analysis of the practical identities of caretakers,

“[D]istributive justice is not just about securing basic resources (in this case, time off, some spending money, and access to activities and groups with whom to make fulfilling connections). It’s about people being able to *convert* those resources into the pursuit of the good as they see it. The demoralization of performing undervalued work while regularly setting aside your own priorities to be transparent for your client undercuts your capacity to perform such a conversion, that is, to take advantage of your share of social resources to promote your own good” (Gedge, op.cit.).

Compensating nurses through economic means is just not enough to offer in return for the valuable work they do. In fact, as Louise Finlayson and James Nazroo indicate in *Gender Inequalities in Nursing Careers*, women place greater importance on personal fulfillment in their careers and having rewarding and interesting work rather than on their level of pay (Finlayson & Nazroo, 79). But when socially structured inequalities channel women into care work and where the social conventions of gender difference allow “hierarchically valued conceptual distinctions”¹¹ to operate in healthcare so as to buttress physicians’ positions of power and domination over nurses, it becomes impossible for caretakers to achieve personal satisfaction in dependency work when their efforts are not recognized as a matter of social importance or concern. Surely, then, what we need is a different approach that involves more than just increased financial reimbursement for nurses since simply throwing money at the problem does little but obscure the fundamental issue. As Jennifer Parks writes in “Recognition and Remuneration for Care workers”,

“For the sake of both care recipients and caretakers, we must take seriously the notion that something is owed, on a social level, to women who are unpaid or underpaid for their caretaking work” (Parks, 495).

The devaluing of nurses, while related in part to how poorly they are financially compensated for the work they perform, pertains much more to a social failure to recognize the necessity of care work—as a collective and not an individual problem (Parks, 489). The universality of the need for and the provision of care must first be acknowledged. For as Parks rightly suggests, “the ultimate goal should be to include caretaking as one of the basic elements of our social system—to deprivatize it—and fashion social responses to what has been treated as a ‘private’ individual problem” (Parks, 490). Conceptualizing caretakers as indispensable—wherein their roles are no longer described as “an item of social liberation – just like a lightweight wheelchair or bus lift” (Shapiro as quoted in Parks, 490) - recognizes the working conditions of nurses for what they ought to be: matters of social concern. For as long as we continue to represent dependency work as predominantly the private choice of women, structuring the provision of care around maximizing economic gain simply encourages the continuation of a vicious ‘circle of care’¹² where women pass in and out of caretaking labour. It is easy to understand why, when nurses become burned out and can no longer take the lack of resources, recognition, and public respect for their career, cutting back hours of availability or taking a break entirely from caretaking labour has become common practice. According to Finlayson and Nazoo’s findings, 63% of female nurses have taken one or more breaks throughout the course of their career (Finlayson & Nazoo, 50). But taking breaks does little to remove the inequity in caretaking responsibilities, nor does it incorporate practical or realistic solutions to the problem. For the broader set of options and opportunities that one might be inclined to associate with increased freedom for

nurses opting out (i.e., defining one's own moral perspectives in matters of sex, love, friendship, work, etc.) is problematic when lacking a pay cheque; and furthermore, respite for individual nurses fails to address the problem of gendered dependency work. Chances are the person replacing a nurse on a leave of absence would be another woman stepping forward to fill her place. After all, patients cannot look after themselves, particularly those in extremely dire medical condition. So, a gendered inequity persists. Therefore, justice and the wellbeing of dependents demand that, while encouraging transparency as vital to good nursing care, we must ease the vulnerabilities of nurses and provide support for the work they have (sometimes not entirely voluntarily) undertaken.

III. Kittay's Connection-based Equality

According to Kittay, we would have an entirely different outlook on society if we were to recognize the unavoidability of human dependency. As it stands, projects in egalitarian theory which attempt to include all persons within their scope, tend to take as the paradigm the free, able-bodied and independent citizen (Kittay, 77). Kittay argues that this approach distorts much of the way society operates and, further, is exclusionary in its overarching representation of all members of society. For when we look around us, into our own lives, careers, and familial relations, it is without question that we have all, at one point or another, either cared for or been the recipient of care from others. And, while we are situated in such relationships of dependence, whether on the receiving or giving end, we may either fail to 'count' as a citizen, or else be responsible for more than just ourselves in the negotiation over just and equal distributions. Decontextualising

citizens and relegating the responsibilities of caretaking to the private sphere situates

dependency outside of our moral and economic responsibilities as a society.

Take John Rawls' work as an example. According to Rawls, the possibility of a well-ordered and just society can be realized if we begin by supposing a hypothetical position from which representatives of all citizens set out to choose principles of justice that their laws shall exemplify (Rawls, 1971, 256). From this hypothetical stance, which he names the "original position", the representatives are "ignorant of their own station in life" so that their collaborative deliberations "guarantee that parties choose principles impartially and, therefore, fairly" (Rawls, *ibid*). Insofar as those situated in the *original position* are entrusted with creating the preconditions for justice in a society, he writes,

"Since the fundamental problem of justice concerns the relations among those who are full and active participants in society, and directly or indirectly associated together over the course of a whole life, it is reasonable to assume that everyone has physical needs and psychological capacities within some normal range. Thus the problem of special health care and how to treat the mentally defective are set aside. If we can work out a viable theory for the normal range, we can attempt to handle these other cases later" (Rawls, 1992, 272 n. 10).

Focusing first on 'normal' needs exhibits precisely what is of concern to Jennifer Parks in "Envisioning a Kinder Gentler World: On Recognition and Remuneration for Care Workers",

"Until this care work is made transparent to us – until we address caretaking needs as social, and not an individual problem – the state will continue to be a 'free rider' using women's care work as an unrecognized subsidy" (Parks, 489).

For it is the very notion of describing health care and disability needs as outside of a Rawlsian “normal range” that represents a fundamental obstacle to nurses being able to provide better long-term care. As Kittay writes,

“...as long as nothing in the construction of the OP assures that any party to the OP will identify their conception of the good, or their rational self-interest, with one who meets the needs of a dependent we have not yet solved the problem of representing the dependency worker. When citizens are idealized as fully functioning, there is no internal incoherence in a theory that does not ensure that parties to the OP represent dependency workers. The theory is simply not concerned with such needs nor with the justice or injustice of how dependency needs are met. But as such a theory has neglected dependency concerns, it is not true to those realities of human life that move us to seek social alliances. Once we stop ignoring dependency, then we are obliged to think of how dependency needs are met in a manner that is equitable to all” (Kittay, 90).

Rawls’ idealization of a fully functioning person requires that “all are capable of honoring the principles of justice and being full participants in social cooperation throughout their lives” (Rawls, 1971, 546). While one may offer that Rawls’ claims were to be interpreted in their applications to individuals over the course of their lives and not specific moments (i.e., Billy, who was once part of the ‘normal range’ but then became one of Rawls ‘difficult cases’, could possibly be considered a full participant despite the present limitations in his capacities), as Kittay points out, the adoption of such a model does not guarantee the selection of principles of justice that balance concerns during periods of dependency (like Billy now) and those during periods of full functioning (like Billy before) (Kittay, 90).

In addition, as nurses take up their own burdens and those of their patients, it is impossible to see how Rawls’ theory can provide any sort of redistribution of contractual

care work without incorporating “a motivational assumption...that recognizes the role of dependency and care in the lives of each of us” (Kittay, 92). For, according to Parks, “Justice for female caregivers cannot be achieved if theories of justice do not account for women unfairly and unequally having to shoulder burdens of care” (Parks, 62). Clearly, when a nurse must defer her needs in order to meet the needs of her patients, it is important that we find a way in which nurses can be both protected and justly compensated (Kittay, 51). Of course, one could argue that nurses are merely required to exhibit this certain characteristic of their selves in a hospital setting and that once they leave they can act as the independent Rawlsian citizen. But as we have already seen, this is a naïve view when women remain largely responsible the brunt of familial care labour.

Clearly, if we are to direct ourselves towards providing support for nurses, developing better care for their patients, and establishing better communication between nurses and families, where we need to begin is not with the separateness of persons but, instead, with the connections we share with others. It is here that I suggest we begin with the following prescription. The dependency approach that Kittay advocates begins with the claim that we are all “some mother’s child” (Kittay, 25). We are all the products of the dependency work of others, whether in childhood, illness, old age, or disability. If we shift our perception of beginning with persons as free and independent and instead move towards recognizing dependency relationships as fundamental to our survival then, Kittay argues, we can make two claims, the last of which I believe directly addresses the situation of nurses: (1) the entitlement to a relationship in which one can be cared for if and when appropriate; and (2) the entitlement to a socially supported situation in which

one can give care without that care becoming a liability to one's own well-being (Kittay,

66). While the former supports the moral obligations dependency workers have to their charges, the latter supports the moral obligations that we, as a society, have to dependency workers. Kittay calls for a principle of *doulia*: a public responsibility to provide support for the caretaker so that she can give without depleting herself and her resources (Kittay, 2002, 243). As a nurse is connected to the larger social order insofar as she is also some mother's child, we must respond to her needs in order to ensure that she receives and is guaranteed the support and assistance she deserves.

Accordingly, Kittay argues that conceivably we can formulate this assistance in the following manner:

"We can make a case for a paid employee who is in a dependency relation, and so has dependency responsibilities, to receive additional pay, benefits, time off, or services, which would enable her to support the dependency relation in a manner suitable to the situation. This would be seen not as a privilege, but as what is properly due citizens of a just and caring society enabling us each to be cared for without extracting an undue burden from those charged with our care" (Kittay, 112).

Implementing these changes enables nurses to be better equipped to deal with the debilitating features of their work and, in addition, serves as a manner in which to bring an ethic of care out of the private realm and into the public sphere. Recognizing the importance of compensation for care, in both financial and social contexts, respects the caregiver as an actual worker like all others who are employed within the public domain. Moreover, this respect cultivates the need for this sort of work to be "de-gendered" through "public programs of educating for dependency work—especially [when it comes to] young boys and men" (Kittay, 143).

The moral sentiment of care has been principally confined to the domestic sphere

while the moral sentiment of justice, as seen in Rawls' principles of justice¹³, has traditionally been restricted to the public domain. Kittay argues that a bridging of these two moral outlooks and the inclusion of care into the public sphere requires, in addition to Rawls' principles of justice, a principle of the social responsibility of care:

“To each according to his or her need for care, from each according to his or her capacity for care, and such support from social institutions as to make available resources and opportunities to those providing care, so that all will be adequately attended in relations that are sustaining” (Kittay, 113).

Working toward such a principle in our own lives as well as within the context of our social responsibilities as a whole helps to dignify the care that dependency workers provide and compensate them fairly for the work that they do. Where patients incapable of voicing their interests are not in a position to reciprocate and where the primary focus of a nurse is to the responsibilities she has for her charges, appealing to any sort of description of societal members as “fully cooperating” or “self-sustaining” cannot possibly work to ground any defensible formulation of equality or a good ethic of care. Rather, what is necessary is the understanding of our “linked and nested set of social relations” wherein we are all interconnected as some mother’s child.

IV. Meyers’ Objection

According to Diana Meyers’, while Kittay’s prescriptions are good, her proposal does little to dispel the coercion that Meyers’ believes upholds the sexual division of labour in caretaking. Meyers’ believes that the normalization of family-based dependency relations—wherein we are directed by Kittay to conceive of each dependency

worker as “some mother’s child” makes exit options for dependency workers

unimaginable (Meyers, 30). She claims that despite setting up a framework which can extend the freedom of dependency work, improve remuneration, incorporate the delegation of dependency work and ensure nurses receive greater financial compensation for their efforts, Kittay has yet to solve the problem of women’s coerced entrance into care work and their tendency to become overcommitted to it (Meyers, 28). Meyers argues that at the end of the day, regardless of how much support caretakers may be able to incur, women remain as default dependency workers when other professionals fail to show up for their shifts (Meyers, 28). Hence, while we may be able to bring male workers into care labour, “only de-gendering and redistributing default dependency work—that is, granting women a full range of allocation options can contravene women’s natural responsibilities and ensure their autonomy” (Meyers, 31) and, as maintained by Meyers, Kittay’s recommendations cannot effect these alterations when “the availability of supplementary dependency services” cannot secure women’s liberty (Meyers, 27).

I agree with Meyers that in order to effect change, we must do more than use public funds to pay out greater wages to dependency workers. As I suggest above in Section II, it will take more than financial compensation to bring about new social attitudes towards public and private care work. Further, while I agree that it will take more than single policy reform to negotiate an increase in care workers, I think that Kittay, also, would agree with this point. Kittay’s principle of doulia suggests that “just as we have required care to survive and thrive, so we need to provide conditions that allow others—including those who do the work of caring—to receive the care they need

to survive and thrive" (Kittay, 1997, 220). Her point then, is that as dependency is

inherent to our existence,

"The well-being of dependents and their caretakers and the relation itself between caretaker and dependent must be seen as requirements of public understanding of social cooperation... That is, it is the responsibility of the public order to ensure that a dependent has a caretaker, that the dependency relation is respected, and that the caretaker is adequately provided for so that her dependency work does not in turn deplete her" (Kittay, 1995, [online]).

When it comes to Meyers' suggestions that women remain the default caretakers when their support fails to show up, it seems to me that Kittay's theory, insofar as it places emphasis on the nested dependencies of individuals—whereby we are all interconnected, introduces more assistance for dependency workers than Meyers' suggests. According to Kittay, for care work to be fairly recompensed, the following is required:

"Making a public commitment to training young boys, as well as young girls, in caring skills. It also requires encouraging men to participate in caring work....the establishment of a "care corps", on analogy with a peace corps or a military corps of young persons who spend a part of their youth engaged in caring work could become a national resource" (Kittay, 2001, 544).

Kittay's suggestions are not "quick fixes". Setting up a social responsibility for care workers, wherein "a citizen body gains skills in, and values, the demands of dependency work" (Kittay, 544) takes time to implement. But, once Kittay's ideas are put into practice, I am inclined to think that, eventually, when workers do not 'show up' for their shifts, additional exit options for nurses would still be available since the interests of caretakers and the needs they possess would no longer be undermined or undervalued in health care systems. In other words, the deprivatization of care work would increase the

resources to which nurses would have access so that women no longer feel trapped or forced into care labour. In socializing care work, Kittay contends we must “publicly acknowledge care as a basic good” which can serve to provide all members of society with a basis for self-respect (Parks, 496). And in doing so, in seeking out such social inclusion and respect for caretakers, I believe Kittay’s proposal can aid in the erosion of the sexual division of labour demanded by Meyers.

Though I support Kittay’s recommendations, I am not sure if her proposal would be enough in long-term care facilities to fully enact change in the quality of care for patients. As I see it, enacting social change so that an increase of resources would be readily available to nurses is only part of the problem. In addition to working towards the introduction of educational programs for men and children that encourage their involvement in care work, I suggest that what is needed on top of Kittay’s prescriptions in order to provide proper care for long-term patients is the establishment of a network of care—where all those who are actively involved in the day-to-day hospital life of the patient (i.e., nurses, family, nursing managers, etc.) can communicate.¹⁴ As I discussed in Chapter 1, part of providing better care involves coming to know a long-term patient as more than their disabilities—as a person. It is here that family plays an important role insofar as they can provide important insight into the interests of their loved one and the sort of care that particular patient ought to receive. Just as I described with the confrontation involving Billy’s wheelchair, when family members and nurses hold conflicting views over what constitutes proper treatment, creating an atmosphere where families and nurses are given the opportunity to conference regularly in a non-

confrontational setting is critical to establishing better care for long-term care patients.

Perhaps then, on top of educational programs, an increased number of nurses, better remuneration and time off, we need to also insist on regularly scheduled meetings between nurses and families where patient long-term care can be discussed.

V. Where to Begin

In my view, then, Kittay's appeal to a connection-based equality must be taken seriously before we can move towards the development of the sort of positive communication between family members and nurses that I am after. In other words, it seems we must ask for a prior understanding of ourselves as connected before we can fully accommodate, appreciate and validate nursing perspectives. If we are to conceive of persons in the manner that Kittay suggests, as some mothers' children, then the vulnerability nurses are subjected to in the transparency of their selves will, in turn, rest upon society as a whole to provide the necessary assistance, support, and resources that caretakers warrant. This not only will help to provide a basis for the public's responsibility to attend to the well-being of nurses but, also, will aid in the acknowledgement of dependency relations as inevitable and fundamental to the continuance of human survival. In particular, Kittay's emphasis on the establishment of mandatory educational programs that encourage the participation of men and children in care work will, I think, help to move towards de-gendering contractual care work. In coming to accept care as a normal feature of human life, men will become more inclined to participate in the "social sharing of burdens" (Kittay, 2002, 245). And, while cultivating a respect and willingness in men to participate in care work may take an

extensive period of time, I believe that Kittay is right to argue that such a transition is entirely feasible with the proper education and incentives. Consider the case of Sweden, where attempts to alter child care patterns have resulted in differential paid leave plans for fathers so that Swedish dads are urged to take time off in order to play larger roles in the caring for their children (Kittay, 2002, 247).

As I argued in section I, many of the protocols set up in hospital policies and health care systems have stemmed from social practice. Perhaps if greater benefits, social assistance and compensation were to be provided to familial caretakers, then paid caring labour would not be fused with the negative overtones with which it is now associated; and, in addition, perhaps men would be more willing to enter into and support this sort of work.

One man to whom we might turn for guidance in the dismantling of the cultural assignment of dependency labour to women is Roger Gottlieb. In caring for his daughter Esther, a fourteen-year-old girl with multiple disabilities, he recognizes that disabled children “require a disproportionate amount of time, energy and money” (Gottlieb, 228). He calls for “massive alterations in our social priorities” which would help to organize our society around need rather than around autonomous individuality (Gottlieb, 231-232). These alterations that he and Kittay suggest, wherein nurses could be appreciated, compensated, and provided with improved working conditions in a de-gendered environment, are necessary precursors to a proper understanding of what constitutes fair requests for care. Otherwise, women will continue to have their lives structured around

their responsibilities to those in need and men will proceed to discount the importance of the equitable redistribution of contractual care work among women and men.

Having considered in this chapter the challenges nurses face, how, then, might the suggestions Kittay and Gottlieb make fit into an ethic of care that accommodates the vulnerability of nurses but, at the same time, respects the vulnerability of patients incapable of expressing their concerns? In dealing with patients of this sort, nurses must interact with surrogate decision-makers who are, most often, members of the patient's family. Yet, as active participants in a society that ought to work towards establishing a greater appreciation and support for the contributions of its care workers, the family of a patient may nevertheless have exceedingly high expectations that a nurse simply does not have the resources to meet. It is here that greater support systems for nurses come into play. Granted families cannot expect that a nurse neglect her other patients entirely for the sake of their loved one, staff shortages can sometimes affect the quality of a patient's medical treatment and his/her hospital life. And, when a family enters into an environment where their loved one is receiving bare-minimum care, it is without question that family members can become hostile and confrontational towards the patient's nurses. I believe that in taking Kittay's connection-based equality seriously and acknowledging the interdependence of human lives, we will be able to establish shared support and an amenable atmosphere for nurses—a feature that is pertinent to the creation of a social environment in which nurses and their patients' family members can participate in conversations rather than confrontations with one another which, as I describe, are fundamental to the improvement of existent long-term care practices.

*Chapter 3 – Restoring Self-oriented Value to Nursing****I. Introduction***

“It is not a nurse and I. A nurse is in myself and I was woven into a nurse. It is like braids. I am this way by weaving a nurse and myself together round and round. So I cannot think and I do not try to think separately from being a nurse and me. I as a nurse and I by nature are woven... When they are woven, it becomes as if I am one piece of yarn. If I were not working as a nurse, I would be a different person. I would not be like I am” (Yukari, as quoted in Gregg & Magilvy, 51).

In part, improving the care that patients receive involves resolving the difficulty that nurses experience in cultivating their personal identities within the context of the demanding expectations of their work. This chapter shall explore ways in which we can bring value into nursing work independently of values that are held in relation to patients. I claim that the possibility of implementing and sustaining adequate patient care in long-term settings depends upon how nurses internalize the meaning and value of their roles as care providers and the manner in which they are taken up in broader social and cultural contexts. I suggest that while the encouragement of increased resources and more personalized relationships between patients and nurses are necessary components of improved nursing care, the realization of self-oriented values are also needed so that nurses can fully ascertain personal meaning in the work they perform.

II. Where We've Gone Wrong

Nurses lack value in their job and this, in part, has been argued by some to be owing to the fact that nurses “are not accomplished in their roles as contractual

caretakers" (Gregg & Magilvy, 47). In a study conducted in 1993, S. Suzuki found that nurses often experienced difficulty in meeting the needs of their patients because "they had many problems with knowledge, common sense, attitude and responsibility" (Gregg & Magilvy, 47). As I see it, however, there are two problems with Suzuki's generalizations. Firstly, I think more attention ought to be directed where it is due—at the insufficient level of resources that affect nurse attitudes, and responsibilities. In my view, attributing the difficulties nurses face to problems of nurse knowledge or common sense simply skirts the real issue—that nurses need better resources in order to fulfill the requirements of their jobs successfully. Further, suggesting that inadequate care is indicative of nursing incompetence, risks placing the burden of coming up with better care entirely on the shoulders of those already doing the work. But as I discussed in Chapter 2, all too often, nurses cannot manage to improve their efforts when they are not afforded the support or the time they need in order to give adequate care. Consider the following example:

"In residential elderly persons' care, an interviewee believed that, owing to time pressures, her inability to spare a resident 10 minutes to help her to start off her knitting was an example of a constraint on resources (here, as in many cases, the resource of staff time) that limited her ability to provide the sort of quality care that was integral to the quality of life of the resident. She explained how spending that time would have provided the resident with an activity for the best part of the afternoon, contributing to that person's contentment and well-being" (Interviewee as quoted in Provis & Stack, 6).

Evidently, limits on care are fundamentally a result of resource constraints. In fact, according to Provis and Stack in the study they conducted regarding workers in health care, several of the obligations that nurses incur through the personal relationships they

have with clients can often be at odds with organizational demands and resource

constraints (Provis & Stack, 5). For instance, in one of their examples, a nurse overrode organizational directives due to the sensitivity she felt for her patients.

“You’re always told how much it costs for linen and that sort of thing...I like to put an extra towel over their shoulders to keep them warm while I dry them with the other towel, so that may not be cost conscious”
(Interviewee as quoted in Provis & Stack, 6).

The relationships that nurses and patients develop generate obligations; particularly when nurses learn to regard their patients as actual persons. Just as this nurse used an extra towel with her patients when she ought not to have done so, the emotional responses and connections that nurses feel towards their patients create emotional commitments that motivate nurses to attend to patient needs despite resource constraints. However, when the moral obligations that nurses have to their charges are limited in their scope because of resource shortfalls, as Provis and Stack point out,

“There is good general evidence that the ambiguity of conflicting obligations and pressures of workload and time are likely to result in staff ‘burnout’, potentially leading to high levels of absenteeism or staff turnover” (Provis & Stack, 11).

Perhaps then, the difficulties in meeting care that Suzuki attributed to the common sense, responsibility, knowledge, and attitudes of nursing staff were instead the result of (1) insufficient time to meet the personal obligations they developed towards their patients and, (2) a lack of collective responsibility within the community to replenish and remedy resources constraints. In placing the onus entirely on nurses and suggesting that bad care stems from a lack of certain qualities or character traits, the social responses and

reciprocity for contractual care workers that Kittay prescribes cannot be actualized and the selves of nurses will continue to be depleted.

Secondly, Suzuki's overarching conclusions allude to the problematic belief that the meaning of nursing work is fully tied to other-oriented values; where the worth of nurses is assessed entirely in relation to the level of care they are able to provide. Perceiving nurses in such a manner, I believe, can do little but establish feelings of meaninglessness, emptiness, and frustration in the work nurses perform. As a gynaecology nurse involved in terminations describes,

"Sometimes I get really mad. No one has any idea what we do for these women. It's a closed world and who wants to know about ugly dead babies—the common attitude is 'well, she can always have another one'. That's not the point is it? And then, of course, what we do for these women is not recognized as anything special—it's just something we do. But could you do what we do? There are not a lot of people who could. You have to really, truly care and yet at the same time be able to cope with caring too much and remain professional. If that's not a skill I don't know what is" (Staff Nurse, May 1997, as quoted in Bolton, 585).

Nursing tasks are often much more than "functionally specific". In practicing the transparency of self that Kittay recommends, where the needs of the patient are discerned by their nurses and their nurses' needs are deferred, caretakers become passionately interested in the well-being of their charges. These special relations that are created by the upholding of the well-being of patients involves more than simply attending to their medical needs, it also involves forming emotional commitments to individuals based upon the obligations nurses feel towards their patients in relating to them as persons. Long-term caring work creates this sort of sustained close attention to individual patients. When nurses, over time, come to know their patients as human beings and are as

compassionate to their needs as resources allow, claiming that they focus exclusively on the parts of the patient that are disabled ghettoizes the work they carry out from the legitimate value that exists in performing a human and moral practice that contributes to the preservation of communities. Thereby, if we are to advocate a nursing approach where nurses make additional efforts to know their patients as ‘individuals’ or ‘whole’ persons, we also must come to recognize nurses as ‘individuals’ or ‘whole’ persons, but it seems to me that when we consider the value society places upon nursing and the value nurses assign to their work, we have yet to formulate the appreciation of nurses as such.

In a descriptive study performed by May Solveig Fagermoen, nurses were asked the following question: “What are the values underlying nurses’ professional identity as expressed through what is meaningful in nursing work?” In collecting answers to her question, Fagermoen began by surveying 767 nurses and then held in-depth interviews with six nurses out of her sampling. Interestingly enough, the survey indicated overall agreement among nurses on four values:

(1) the other-oriented values, *upholding humaneness* and *attending to needs for help*. The former reflected a holistic perspective, an emphasis on the patient’s individuality, and the nurse’s humaneness, presence, and empathetic understanding. The latter reflected actions aimed at caring for, comforting and helping the patient; and (2) the self-oriented values, *intellectual stimulation* which referred to the cognitive aspects of work, e.g. problem-solving, variation and learning, and *personal stimulation* which reflected how nursing affects the nurse personally, e.g. work is joyful, and one grows as a human being. (Fagermoen, 437)

Fagermoen’s findings, at first glance, seem to support precisely what the professional identity of nurses has come to insinuate—that the actualization of self-oriented values in nursing is currently possible. Upon conducting interviews with nurses, however,

Fagermoen's results offer quite a different position. The interviews revealed that few self-oriented values were identified in the narratives the nurses presented. Though in her analysis, Fagermoen attributes the overemphasis on other-directed values and the lack of self-oriented values to "the special focus on patient-care situations in the interviews as compared to the survey's focus on nurses' work in general", I am inclined to think that there is more to their emphasis on other-directed values than the simple justification Fagermoen offers.

Consider the results of her interviews. While the sampling of nurses interviewed is acutely limited in comparison to the number of nurses that completed the survey, all the values identified in the interviews by the six nurses involved the patient as the point of focus. Table 1.1 depicts these patient-focused values and how they were deemed to be reflected in nursing practice.¹⁵

Table 1.1

Value	Description
Dignity	found in actions emphasizing inherent worth of patient (i.e., taking patient seriously, restoring appearance through physical care, advocating for a dignified dying)
Personhood	established in actions aiming at knowing and treating patients as persons in their individuality, not as mere medical conditions
Autonomy	Letting the patient keep something of herself to herself
Integrity	reflected in actions emphasizing patient as a whole being with a past, present, and future
Being a Fellow Human	found in recognizing the patient and nurse share the same humanity (i.e., nurses actively make an effort to understand patient's situation from patient perspective and to be with patient as a person, not just as a professional)

While each of these values is important in instituting better care for long-term patients, suggesting, as table 1.1 does, that all values in contractual care work are embedded in those that are other-oriented risks neglecting how nursing affects nurses personally. For in setting up the values which underlie professional identity in nursing to reflect purely other-directed principles, I argue that two problems are created. (1) The actualization of the values depicted in table 1.1 is dependent upon a considerable investment of time and energy on behalf of nurses—something that, as we have already witnessed, is rarely available. When nurses are assigned large groups of patients and provided with little relief from the stress of their work, the close and continuous relationships that are needed for the realization of other-oriented values can leave nurses exhausted and unfulfilled. Even in light of her view that the self-oriented values of nurses can be mediated through those that are other-directed, Fagermoen willingly acknowledges the challenges that providing for nurses self-expression through the materialization of other-oriented values can create in the face of insufficient resources,

“Contextual factors, such as shortage of personnel and time, were perceived to affect the opportunity for providing quality nursing care, which in turn was experienced as a strain, and for some created a feeling of meaninglessness” (Fagermoen, 440).

However, it is hard to see how Fagermoen can make this claim and state that for most of the nurses in the survey and all the nurses she interviewed “the value of altruism or care for the patients’ health and well-being appeared to be an over-riding value” (Fagermoen, *ibid*) in conjunction with her conclusions that the realization of self-oriented work values in personal outcomes is possible. For it seems to me, that the *personal stimulation* nurses

identified in the survey as an important self-oriented value, insofar as it is based upon the enjoyment nurses are able to get out of their work and the contributions nursing makes to their growth as human beings (Fagermoen, 437), can hardly be mediated through the values table 1.1 identifies. It seems to me that Fagermoen is skirting the issue and has overlooked what her findings clearly suggest: nurses are not being provided with the means to actualize their self-oriented values and this, in turn, affects their ability to feel rejuvenated in the work they perform, contributes to feelings of emptiness, and leaves them unfulfilled in their roles as contractual caretakers.

The second issue that I take with claiming nurses have access to self-directed values through those that are other-oriented is that it creates the illusion that the identities of nurses are sustained purely in terms of the contributions they make to their patients. All of the values identified by the nurses interviewed reflected the care of patient health and well-being as what underlies nurses' professional identity. And, in part, this is important when nurses are to act as transparent selves and attend first to the needs of their patient before their own. But this ought not to mean that the needs of nurses are to never be met or in any way taken up. This is precisely why Kittay makes the call for social reciprocity and introduces the principle of *doulia* so that the selves of caretakers can be replenished, their needs met, and, hence, they too can survive and thrive. It seems, however, that when we make the mistake of suggesting that the values which contribute to the self-formation of nurses pertain entirely to those which are other-oriented, we are alluding to the idea that, at present, nurses ought to feel rewarded and content in their roles as caretakers (as their self-oriented values are perceived to be actualized) and any

inadequacy in care is something they must work harder to fix, independently of social assistance.

Consider Provis and Stack's discussion of nursing obligations and resource policy. With regards to the relationships nurses form with their patients, they write,

"[I]t generates some degree of obligation on the participants in the same general sort of way that friendship generates obligations" (Provis & Stack, 8).

But I claim that in comparing the nurse-patient relationship to that of a friendship, we fully discount the fact that most nurse-patient relationships are one-sided—particularly, those that involve the long-term care of severely disabled individuals. A friendship, on the other hand, is a relationship that two people come into by choice, where both parties can reciprocate and support one another. People can *walk away* from friendships. When two people no longer get along, they can *choose* to go their separate ways, and the obligations they may have incurred throughout the course of their relationship no longer apply. However, with nurse-patient relationships, nurses cannot choose to walk away from their patients. They must sustain that relationship even when a patient cannot provide reciprocity or mutual recognition for the self of the nurse.

Describing the nurse-patient dynamic as a friendship gives the impression that care work is "voluntaristic" where women freely engage in care work as a 'labor of love'—a description that we have already seen fails to encompass contractual care work and the challenges it presents for those who engage in it. Hence, the obligations that bind nurses ought hardly to be compared to those that are generated in friendship as friendships are

viewed as private affairs—something we are trying to take out of nursing in order to

create a broader sense of obligation to nurses in society.

In addition to claiming that the obligations created in friendship and nurse-patient relationships are analogous, Provis and Stack go on to argue that nurses, in recognizing their patients as persons, require discretion and time to meet patient needs (Provis & Stack, 10). While they recognize that the level of resources often falls short of what nurses need in order to provide for their patients, they stress that contractual care workers have a ‘special’ responsibility to remedy the resources they lack. They write,

“Meeting such individual obligations requires [nurses] to have discretion and resources, including, among others, resources of time. Our studies showed that all too often care workers are not afforded the resources they need to meet individual obligations, which may be a shortcoming of either policy direction or community resource allocation. Although they cannot as individuals be expected to overcome these resource shortfalls, it may be that care workers do have a collective responsibility to do what is possible to remedy them, and that they have individual obligations to assist in meeting that collective responsibility to an extent that depends on their skills, training, and experience” (Provis & Stack, 13).

This, as I see it, is a fairly unfeasible expectation to place upon nurses—even in light of the collectivity that they suggest. In highlighting the shortage of time and resources that nurses presently experience, how can nurses be expected to find additional time to accept full responsibility for raising questions about hospital policies and the allocation of resources? For, as I see it, nurses would need better time resources in order to even manage *discussing* better resources of time. After all, we cannot ask nurses to place the obligations that they feel towards their patients on hold while they engage in negotiations that pertain to the inadequacy of resources available. But if there is no increased support,

and nurses are the ones believed to “see more clearly what problems there are” (Provis & Stack, 11), then with the insufficient time nurses have to meet the obligations of their patients’ needs, confronting shortfalls in resources will inevitably take a backseat to patient care responsibilities.

In backing their claims that nurses are to take full accountability for better funding and resources, Provis and Stack attribute their suggestions to their belief that nurses “know more than the general public about the shortcomings of ‘managed’ care” (Provis & Stack, 12). In my view, however, this encourages the continuation of ignorance among those outside of care work. Arguing that members of the general public are ill-informed of the resource constraints in health care due to a lack of collective responsibility on behalf of nurses to lobby for better support, I think fails to address that nurses’ needs must be taken up as a social problem. Instead of placing the burden on nurses to improve the level of care they can offer patients, we would be much better off if we were to begin with the moral responsibility that we all have, as the greater social order, to improve the resources to which nurses have access and provide better support for their care efforts.

Of course, one may wish to counter with the point that nurses themselves *are* best able to make their case for more support. After all, they experience resource shortages first-hand, so why wouldn’t they be ideal candidates for recognizing the needed improvements throughout health care systems? To be clear, I am not arguing that nurses and their unions be left out of lobbying for better support but rather that the burden not be shouldered by them exclusively. With high stress levels and insufficient staffing, the limited time and energy nurses have available prevents the very possibility of raising the

level of consciousness about the plight of nurses to the level of awareness that Provis and Stack are suggesting. This is illustrated by the following statistics as outlined by the Department for Professional Employees¹⁶:

- Among nurses there are high rates of emotional exhaustion and job dissatisfaction which are strongly associated with inadequate staffing and low nurse-to-patient ratios. Each additional patient per nurse corresponds to a 23% increased risk of burnout, as well as a 15% increase in the risk of job dissatisfaction.¹⁷
- A 2000 survey reported a satisfaction rate of just 69.5% among RNs, substantially lower than the 90% overall job satisfaction among professionals. This dissatisfaction is clearly linked to the departure of RNs from the nursing work force. In a survey conducted by the American Nurses Association, 33% of nurses under the age of 30 stated their intent to leave their present job within the year.¹⁸
- A study by Peter Hart & Associates found 50% of employed RNs had considered leaving patient care within the last two years for reasons other than retirement, and 21% of them said they expect to quit within five years. Nurses who are considering leaving patient care and those who have quit consistently cite better staffing levels and more time with patients as key to persuading them to stay or return to patient care.¹⁹
- Some nurses have left hospitals to work in less stressful environments. In 2000, an estimated 21% of all acute care hospital nurses left their positions.²⁰ The proportion of RNs who work in hospitals fell from 66.5% in 1992 to 59% in 2000.²¹

Insofar as there is such a high turnover rate within nursing, it seems to me that nurses are largely in need of additional lobbyists for their concerns. They cannot *themselves* be expected to create recognition of the worth and the particular challenges in the work they do. In so containing the responsibility to nurses, the resources that are needed to improve patient care and reductions in the level of stress that nurses presently bear are challenges that nurses ought not to be expected to face even collectively given their elevated turnover rate and the consistency that is needed in order to effect change.

From the evidence we have encountered in this section, the self-oriented values of nurses have received little attention. The reasons for this oversight that I have suggested include arguing that the responsibility of better care be left entirely up to nurses, that other-oriented values can actualize the personal stimulation of nurses, and that changes in nurse attitudes are what create a lack of value in the job. The inaccuracy of each of these reasons, I believe, has contributed to feelings of emptiness and frustration which has resulted in nurse ‘burnout’. In providing nurses with the means to actualize self-directed values, I argue that better care can be instituted, thereby preserving the integrity, dignity, and personhood of the patient.

III. Maintaining Transparency in Light of Actualizing Nurses’ Self-Oriented Values

Recall that on Kittay’s account, the demands of nursing favour “a self that defers or brackets its own needs in order to provide for another” (Kittay, 51). In characterizing this self one that is *transparent* and arguing that it is a moral requirement of nursing that nurses make such a self indispensable, the identities of nurses can easily be lost or forgotten. In asking nurses, at times, to benefit another at an expense to themselves, something must be done in order to ensure that the value in nursing does not entirely get defined in terms of values which are other-directed.

Given the cited research on nursing values, we can conclude the following: the self-directed values of nurses as professionals mainly are not being met. In particular, as Fagermoen’s research revealed, part of what nurses aspire to in their work is the perceived possibility of *intellectual* and *personal stimulation* within nursing practices. As

it stands, the conditions of their work are incompatible with these aspirations.

Undoubtedly caring for others can help nurses to feel good about themselves and the selfless work they perform, but when the number of patients exceeds the level of what a nurse can properly manage, it becomes difficult for nurses to find pride in their work, let alone find enjoyment in the tasks they perform when expectations exceed the means of what they able to give. We need to move in the direction of creating conditions for nurses that can set improvements in nursing practices into motion. Establishing an ethical mandate which can make, on the whole, positive experiences in nursing more readily available to nurses requires improvement in opportunities for delegating care tasks and the heightening of social awareness of the necessity for social support in care work. Raising a social understanding which appreciates the demanding features of care labour begins with disassociating self-oriented values of nurses from those which are other-directed. To this end, making persons socially aware of the lack of personal values that nursing is able to fulfill for its participants (a feature morally required of all human practices) and combining this with Kittay's improved educational structures for those external to long-term care practices is a good beginning to getting people to think seriously about what they can offer to improve the working conditions of nurses. This support, insofar as I have already added to the institution of Kittay's educational programs on care with suggesting a network of care—where all involved in the day-to-day care of patients can meet to discuss options, resources, and treatment—must be taken up outside of hospitals so that the inadequate resources that communities allocate to care can be improved and restructured. Perhaps in setting up the network of care that I

suggest, where the families of patients can regularly speak to nurses and come to understand the shortage of resources they incur, families can then take those concerns back into the community and advocate for the introduction of more time, energy, and assistance in nursing. After all, nurses cannot be expected to educate the general public about the shortcomings of care that they experience in light of resource constraints. So, I suggest that part of establishing the collective responsibility that we have to do what is possible to remedy the challenges nurses face includes taking the productive conversations that a network of care would set up between nurses and families and utilizing their content to advocate the interests of both patients and nurses in wider social contexts. Since nurses are unable to walk away from the moral obligations they have to their patients in acting as transparent selves, maybe the families of the patients can step in and accept partial responsibility for raising questions about policies which contribute to the inadequate care their family members' nurses are able to provide. It is my belief that in aiming at the collective obligation of the general public to collectively reciprocate nurses for the care they provide, nurses will no longer experience nurse 'burn out' and they will be able to achieve the self-directed values they have the right to obtain. Kittay's suggestion that we adhere to the maxim that "we are all some mother's child" where asserting that "I, too, am a mother's child" is to assert that I am due treatment compatible with or analogous to the treatment a mother renders to a child" (Kittay, 68) can properly serve as a mandate for the collective responsibility we all have to ensure that reciprocity and support for nurses are carried out. However, I think that in addition to Kittay's maxim, if value is to be attributed to nursing outside of the values that are other-directed,

we ought to make very clear the stipulation that nursing is *not* self-sustaining. And misconstruing it as such, where nurses are expected to silently carry the burden of long hours, patient overload, and insufficient support, contributes to the very poor levels of patient care existing in long-term care facilities that we are striving to avoid.

Chapter 4 – Socializing Patients for Acceptance

I. Introduction

I begin with a quote from Susan Wendell's book, *The Rejected Body*,

"The distinction between the biological reality of a disability and the social construction of a disability cannot be made sharply, because the biological and the social are interactive in creating disability. They are interactive not only in that complex interactions of social factors and our bodies affect health and functioning, but also in that social arrangements can make a biological condition more or less relevant to almost any situation" (Wendell, 35).

Social attitudes and institutions are crucial in determining what counts as 'normal'. And when it comes to disability, the expectations of performance which stem from the unacknowledged assumption that everyone is healthy, able-bodied, and young serve to exclude the experiences of those who are disabled. Physical and mental limitations are stigmatized, and disabling barriers are set up in such a manner that disabled persons are disempowered and segregated from those who are able-bodied. In this chapter, I will discuss the prejudice disabled patients face and how it affects the care they receive, the impact the disabling barriers have on their families, and why families feel a need to place tremendous emphasis on 'socializing' their loved one for social acceptance. I shall claim that remedying the stigma of physical 'imperfection' involves tackling the physical ideals

of our culture. In supporting the claims of Jenny Morris, I argue that dismantling the barriers those who are not able-bodied face requires that we separate out ‘impairment’—the features of disabled bodies and minds—from the way people *react* to these differences (Morris, 2). I suggest that in validating disability as difference we can move away from assimilating people with disabilities into non-disabled social lives so that their differences are no longer taken up exclusively as ‘abnormal’, tragic or needing to be ‘cured’. Eliminating medicine’s attraction to ‘normalcy’, in turn, will lead to improvements in the way that nurses recognize disability as difference. And this, I declare will aid in honouring patients as persons and instituting better care to long-term patients.

II. The Disability Stigma

It is without question that there are very specific ideas about what counts as physically ‘attractive’ in our culture. When we are continually bombarded with media-soaked images of men and women exhibiting the ‘ideal’ body type—slender, youthful, and, of course, able-bodied—deviations from this ideal are readily met with social resistance, rejection, and fear. According to Wendell, “disability carries a stigma that many people want to avoid, if at all possible” (Wendell, 25). Designating persons as ‘disabled’ often results in the tendency of social attitudes to classify individuals with disabilities as being *entirely* or *fully* disabled. Classifying persons who are not able-bodied in such a way Wendell thinks,

“...is often created by the inability or unwillingness of others to adapt themselves or the environment to the physical or psychological reality of the person designated as ‘disabled’; and people with disabilities often

regard the accommodations they make to their physical conditions as ordinary living arrangements and their lives as ordinary lives, despite their medicalization by professionals and most people's insistence that they are unusually helpless or dependent" (Wendell, 30).

So much of what causes the struggles of people with disabilities is due to the social failure to create ability and options for disabled persons. And when people with disabilities are met with widespread perceptions that their disability makes them disabled *in all contexts* to the outside world, the obstacles that the radically disabled (e.g., Billy) face are even more severe when the level of impairment requires complete dependence on others for advocacy and the basics of life. One clear example of how socially influenced attitudes can negatively impact the lives of the radically disabled is the diagnosis Billy's doctors reached regarding his mental capacities. Recall that Billy is described by his doctors as having the same mental functioning and understanding as a two-year-old child. That said, I often witness Billy laughing and smiling when his family tells him stories or jokes far more advanced than a two-year-old child would be able to comprehend. When I encouraged his regular physician to conduct further testing to more accurately determine his brain activity levels, I was met with extremely adamant resistance since, in his eyes, Billy's life would be no different even if the age assigned to his mental capacities were to be assessed slightly higher than where his physicians believed them to be. It seems then that instead of socially responding to and providing improved assessments and treatment for people with disabilities, there exists a tendency to shun their experiences which leads to the omission of their perspectives from cultural representations of life entirely in society. As a result,

“The lack of realistic cultural representations of experiences of disability not only contributes to the ‘Otherness’ of people with disabilities by encouraging the assumption that their lives are inconceivable to non-disabled people but also increases non-disabled people’s fear of disability by suppressing knowledge of how people live with disability” (Kent 1988; Dahl 1993, as quoted in Wendell, 43).

Because disabled people’s experiences are not integrated into culture and social attitudes infiltrate and influence hospital practices (as we saw earlier in the traditional assignment of specific gender roles to nursing), the families of radically disabled persons often hide or mask their family members’ ‘imperfections’. I argue, however, that marginalizing those who are extremely impaired in a non-disabled society merely serves to protect the social norms that stigmatize disability and risks failing to provide adequate resources for people with disabilities.

III. The Socialization of Disability for Acceptance

Masking disability or making it less noticeable is a practice Kittay argues is largely taken up by families of severely disabled persons. When social acceptance is understood against the avenue of ‘normalization’, those who are ‘different’ are encouraged to eliminate or conceal their differences. “Socializing” disabled persons for acceptance then is a result of the repugnance associated with the disability stigma (Kittay, 166). Even in her own experiences with her daughter Sesha, Kittay found herself succumbing to the social pressures that surround disability.

“I often find myself far more concerned with the clothes Sesha wears than I would be with my able child and with making sure her clothes or wheelchair are not in any way soiled, that is, with being certain that Sesha presents a face to the world that is as attractive as possible. This is so that the first response to her is as positive as I can make it” (Kittay, 166).

In societies that regard independence as desirable, there is little room for people who are unable to live without relying on others. In efforts to avoid being categorized outside of the paradigm of humanity (those who are able-bodied, independent, self-sufficient) that societies exclusively validate, families of radically disabled persons often respond to social disgust by covering their loved ones' limitations as much as possible. This, according to Cheryl Marie Wade, places persons with disabilities into a new category: "the able-disabled".²²

This process of looking a little less disabled is somewhat of a sad need because it is the way in which families hope to communicate to the general public that their family members matter and are deserving of good care. However, this need can be particularly dangerous when socializing disabled persons for acceptance places their health in jeopardy. For instance, in my experiences with Billy's family, ensuring that Billy looked 'presentable' was of utmost importance to his loved ones. If his face wasn't washed, his hair a mess, or his shoes were missing, his family would take just as much offense to nurses neglecting these 'surface' needs as they would to the neglect of his more critical needs (such as suctioning his tracheal tube or hooking him up to oxygen). I distinctly recall an instance where one of Billy's family members discovered that his nurses had cut the backs of his shirts so that they could get him into his clothes without irritating his tracheal tube. His relative was irate that his shirts had been cut because she claimed it made Billy look "poor" and "unable to afford decent clothing" Even after the medical reasons his nurses offered in support of cutting his clothes (such as they were concerned they would irritate his tube if they opted to force the clothing over his head, and his

bodily swelling could, at times, cause his shirts to be uncomfortable if left uncut), Billy's relative remained extremely upset by his nurses' actions. This is illustrative of how meeting this need can potentially be unsafe for the welfare of the patient. Clearly, we need to find a way to redirect our focus towards improving the quality of life of the patient and limit the influences that social attitudes in their perpetuation of body idealizations create.

The actions of Billy's family, I believe, are indicative of the following two problems that presently operate in social responses to the lives of people with disabilities. First, social acceptability is dependent upon one's ability to meet the requirements of normality that Wendell describes: "body size, carriage, movement, gesture, speech, emotional expression, appearance, scent, ways of eating, and especially control of bodily functions" (Wendell, 88). How close one can come to shaping their identity to meet these social standards then wrongly gets taken up as carrying the same (if not more) importance as meeting the needs of disabled people's physical limitations, pain, and illness. More importantly, the consequences of denying or hiding bodily limitations, I believe, skirt issues of the availability of resources needed to meet medical needs and contributes to improper understanding of the actual lived experiences of persons with disabilities.

To be clear, I'm not suggesting we should neglect the 'surface' needs of patients. In fact, I think there is some moral weight to the reactions of Billy's family outside of my view that their responses are caused, in part, by a lack of cultural representations of the positive experiences with disability and the assumption that everyone must appear as 'normal' as possible. In fact, I see it as part of the coping process for families to make

those who are radically disabled as presentable as possible—as doing so can make families feel more included in their loved ones' day-to-day care or give them the opportunity to physically display how well-loved their family members are. But where we must be careful is to ensure that socializing the radically disabled does not establish a slippery slope wherein superficial needs of patients eventually become prioritized over those that are life-sustaining.

Herein lies the second issue that I find to be operating in social responses to those who are disabled. We must take the focus away from 'hiding' or 'covering up' the disabled bodies of patients in long-term care and instead move towards improving the quality of their experiences by accepting patients for who they are—not how well they fit into the physical ideals of their culture. Nevertheless, part of accepting patients in their entirety requires that their physical appearance is maintained in the very same way that we would all wish for our basic physical needs to be met if we were incapable of meeting them on our own. For part of recognizing patients as persons involves understanding the limits of their capacities and compensating for them to the best of our abilities. And when a patient's hair is left deliberately uncombed, their teeth unbrushed, their face unwashed, this alludes to the idea that persons with disabilities are not due the same respect we expect for ourselves and that when their disabilities are beyond the possibility of being masked or cured, how they are presented to the world ought not to matter . In Billy's case, due to the medication he is administered, he experiences significant swelling in his face, feet, and hands. On several occasions, I have found that his hands (due to the fact that his fingers are pressed tightly together on account of the swelling) emit a foul

odour because they haven't been washed thoroughly. Insofar as this can cause irritation, redness, and possibly infection between his fingers, I took up my concerns with one of his nurses to which she replied,

"Billy's hands are different than ours. They smell because he sweats differently than you or I. I clean every patient the same way that I was taught to clean them. It isn't my responsibility to clean someone differently because they have extenuating circumstances beyond my control. This is the cleanest his hands are going to get" (Staff Nurse, February 9, 2005).

It is one thing to claim that time constraints or staff shortages prevent thorough washing of Billy's hands, yet it is quite another to argue that Billy's hands cannot be cleaned because they are 'different' Invalidating the right that Billy has to good care based upon physical attributes that are beyond his control, I believe, perpetuates the view that disabled persons are 'abnormal' and the negativity that surrounds their bodily experiences need not be challenged because they are not 'us'. In my view, changing the attitudes toward the 'otherness' of patients like Billy does not mean that we ignore the physical appearances of patients altogether—after all, everyone is entitled to having their basic needs met; including those which relate to personal hygiene. Rather, adjustments to social attitudes toward those who are severely disabled must come about by re-conceptualizing 'disability' so that it neither devalues disability nor suggests that persons with disabilities are non-eligible for better care. The focus then ought to not rest entirely on socializing patients for acceptance—wherein their differences are hidden or minimized - but with a model that challenges the discrimination and prejudice that disabled patients face.

IV. Silvers' Neutral Conception of Disability

According to Anita Silvers, “Disability is the idea that currently guides the grouping together of individuals perceived as lacking *normal* powers of body or mind” (emphasis mine, Silvers, 471). It is without question that there is considerable disregard for disability and this has, in part, contributed to the inadequate care that severely disabled patients presently receive. That's why in raising questions about the quality of care of long-term disabled patients we must look at how disability is classified and whose interests present definitions of disability tend to serve.

At the outset of this section the perception of disability that was presented, insofar as it feeds into the incorporation of value-laden concepts like ‘normal’ into conceptions of disability, *devalues* the experiences of disabled persons. Suggesting that the disability label entails “otherness” or deviance from social norms seems to support and condone the assumption that there is something intrinsically ‘bad’ about being disabled. Insofar as this can lead to social attitudes which encourage socializing persons with disabilities for acceptance and risk threatening the welfare of the radically disabled, something must be done to provide better care for long-term disabled patients when remediation of their impairments is not possible (Silvers, 475).²³ Silvers believes that we need to extract the emphasis placed on society’s “fatal attraction” to normalcy out of the disability model and impose what she claims to be a “neutral methodology” of disability (Silvers, 476-477). In her view, “such conceptual neutrality in respect to the nature of disability helps disentangle the limitations associated with disabilities that are medical problems from the limitations that are social problems” (Silvers, 477). Rightly, Silvers argues that the

disabling barriers that surround disability are not entirely a function of the physical limitations of those who are disabled. Rather, they are largely created out of social fears that increased social participation for disabled persons invites injustice to non-disabled people insofar as societies mistakenly view the special compensation and protections already set in place for disabled persons as privileging (Silvers, 481). However, in light of the bodily ideals that cultural pressures promote,

“..if the cultural concept of the ‘normal’ body is a young, healthy, energetic, pain-free body with all parts present and a maximum range of graceful movement, then experiences of the negative body need not be confronted and understood. They belong to those with disabilities and illnesses, who are marginalized, not ‘ordinary’ people, not ‘us’ (Wendell, 91).

Clearly, claiming that special considerations privilege disabled persons is hardly true when standards of physical ‘normality’ constantly remind those who fall outside the ideal that they need to measure up. Developing a neutral notion of disability, Silvers argues, will aid in eliminating the segregation and exclusion that disabled people currently cope with.

To start, Silvers thinks we need to adopt a neutral position concerning the intrinsic value of being disabled. We need to give up, she writes, “assuming that disability is intrinsically bad” (Silvers, 475).²⁴ She calls for attention to be given to deconstructing the view that medicine devalues disability, but not people with disabilities (Silvers, 476). Insofar as the lives of disabled persons are intertwined with the physical impairments they endure, one cannot exclusively refer to their medical conditions without making some unfair assumptions about disabled persons (especially in cases of the radically disabled—

where they are particularly vulnerable to the perceptions of those upon whom they rely for their care) And, to the extent that medicine is influenced by social attitudes, she claims that the vulnerable position these assumptions put patients in stems from societal aversion towards persons with disabilities (Silvers, 477).

In removing each of these negative components that presently make up social views on disability, we must incorporate “a conceptually neutral standard for the dominant cooperative scheme” which “will identify justice with the most maximally rewarding inclusive scheme, not with divisive schemes that entitle some privileged individuals to maximal benefit” (Silvers, 481-482). Our goal, then, ought to involve the inclusion of disabled persons into societies through the formulation of a paradigm that recognizes the functional diversity of all communities (able-bodied, partially impaired, radically disabled, etc.). In this regard, the bar to being declared disabled would weigh one’s “differences” of disability only after universal inclusion of all non-disabled and disabled persons into the community. By doing so, Silvers’ claims there is no suggestion of separateness between disabled and non-disabled persons which, she believes to be desirable, as neither side would be considered more privileged than the other. In addition, part of setting up such a neutral framework involves what Silvers describes as the establishment of “conceptual neutrality” where the negativity is stripped from the nature of disability. Persons (disabled or able-bodied) will be entitled to maximally rewarding inclusive social arrangements where the distribution of resources is no longer afforded through divisive schemes that entitle some privileged individuals to maximal benefit in certain social areas (e.g., health care resources).

As I see it however, Silvers' neutral account—though set out to benefit disabled persons—may work against her aims and encourage the stigma that we are working to eliminate in present social attitudes toward disability. Attempting to include disabled persons into non-disabled societies suggests that disabled persons “fails to appreciate the possibility that having at least some disabilities may be, like membership in some other groups that are stigmatized, as good as or better than ‘normality’” (Wendell, 59). What is needed, I believe, is a conception of ‘disability’ which can actively question the values of the majority and work towards properly revaluing and understanding disabled differences so that disabled patients’ needs can be more adequately met in long-term care facilities.

V. “Anatomy is not Destiny”

There is a difference, Jenny Morris thinks, between impairment and disability. For her, ‘disability’ refers to “the disabling barriers of unequal access and negative attitudes” that social attitudes create, whereas ‘impairment’ relates to “the functional limitations of our bodies and minds” (Morris, 2). Where we get it wrong, Morris argues, is when we conflate the two and suppose, as societies regularly do, “that impairment is an inevitable tragedy which can only be alleviated by cure or death” (Morris, *ibid*). It is this approach which leads to the segregation and exclusion of disabled persons and ultimately alludes to the idea that disabled lives do not matter or they are not worth living (Morris, 3). Morris believes the only way we can get things straight is to dissociate impairment (actual physical and mental limitations) from the prejudice and discrimination that disabling barriers introduce for disabled persons. We must focus on determining which restrictions result from impairment, which from disability, and upon making such

distinctions, how we can go about “campaign[ing] against the disabling barriers and

attitudes which so influence [disabled persons] lives and opportunities” (Morris, 9).

For some, there are additional requirements that disabled persons must have access to if their personhood is to be fully realized. Recognizing these requirements involves recognizing the negative aspects of impairment without undermining the experiences or lives of persons with disabilities (Morris, 10). Rather than hide the negative features of disabled lives, we need to write about, investigate, and give a voice to personal experiences of disabilities so that disabled persons are no longer subjected to intense discrimination. As Morris writes in reference to herself and others who are not able-bodied,

“The problem is that if we don’t express the experience of our bodies, others will do it for us. If we don’t confront what we need as a result of illness, pain, chronic conditions which inhibit our lives, then health services and support services will continue to be run in ways which disempower us...Most importantly, if we don’t take over the representation of the negative aspects of impairment then its meaning to others will continue to undermine us” (Morris, 10-11).

Hence, instead of opting, as Silvers recommends, to remove negativity from disability, it seems better to begin with what Morris recommends—a common understanding of us all as persons, whereby disabled persons can articulate the negative aspects of their impairments and represent their own realities outside of disabling connotations that societies have traditionally associated with their lives.

In encouraging Morris’ model in long-term care settings, caring for disabled persons would no longer centre around providing care that will hide or mask physical and mental impairments. Families would no longer slip into situations where or ‘including’

their loved ones back into societies risked putting their family members' health in danger because their loved ones' would no longer feel the need to hide their limitations. Further, I perceive that by taking the negative aspects of impairment up in communities and dissociating them from discriminatory social constraints, support for patients and their nurses would improve drastically. Attention would be directed where it is most needed—to a better understanding of how to provide practical assistance to both nurses and their patients—as opposed to where the attention presently resides—with social attitudes that view disabled persons as abnormal or pitiful.

Enabling the experiences of disabled persons to move away from the assumption that impairment dictates quality of life creates social awareness and responsibility where it is unequivocally necessary—in the care and treatment of disabled persons in long-term care situations.

*Chapter 5 – Procuring Better Care for Long-term Patients:
Putting “Billy’s Network” into Practice*

I. Introduction

Throughout this project I have openly shared my personal experiences with Billy in an attempt to get us all to think sincerely about the inadequacy of care that long-term patients currently receive. What I have learned from my time with Billy is that any progressive movement toward bettering patient care must first begin by looking seriously at the various perspectives from which all participants in care relationships originate. Therefore, the perspectives of nurses, family members, patients, and their communities all must be factored into discussions of care. Insofar as we have seen that nursing cannot be

characterized as voluntary when it is mostly women who take up nursing roles, the privatization of nursing is, in part, responsible for the social negligence exhibited in social attitudes toward long-term care. It is fundamental that we work to deprivatize nursing so that matters of care become public affairs of social concern. And fostering social attention to care requires precisely what I have discussed—providing access for nurses to their self-oriented goals of personal stimulation and growth through increased resources, support, assistance, funding, and time off. As a collective, we have a social responsibility to recognize the interdependency in our lives to which Kittay speaks and to provide the necessary social reciprocity she urges in order to sustain good care relationships. But while these increased resources are vital to the project of improving care for long-term patients, most importantly I believe they are only as effective as the attitudes that are behind those who provide them. While undeniably an abundance of resources is needed to improve care for patients like Billy *unless* those resources are used in conjunction with nondiscriminatory attitudes toward those with disabilities, they are virtually as ineffective as the resources to which nurses currently have access. Otherwise disability will continue to be stigmatized as what is ‘other’ and the much needed attention and resources that can improve the functioning capacities of the radically disabled will be neglected to be assigned where they are much needed. In addition to finding ways to work toward changing social attitudes of disability and establishing support for nurses, we must generate awareness and respect for the personhood of patients. In Billy’s case, once nurses are properly reciprocated for the work they perform and more persons are directed into care work via Kittay’s educational programs and social recognition of

doulia, I argue that with regard to long-term care, these additional resources must in part be utilized to formulate structures which encourage fluid conversations between Billy's nurses and his family members so that his nurses can come to view Billy as more than his medical conditions make him out to be. These conversations are entirely viable if we keep to the collaborative standard for surrogate-consent decisions that I set out earlier. To the extent that each of these changes will contribute to actualizing better care for long-term care patients, it is the latter on which I shall focus for the remainder of this chapter.

II. Billy's Network

Recall the *collaborative standard* I set out in chapter 1 for surrogate decisions concerning long-term care patients:

In matters of surrogate decisions in long-term care, (i) the interests of the patient, her family, and the nursing staff are all to be considered morally relevant and (ii) medical and non-medical decisions for the patient must result from the collaboration of all persons involved in her care.

One of the most important features of this standard is that it supports a conversational format in which there are no hierarchical distinctions or privileged positions marked out. Though I want to make it clear that this does not mean the differences between nurses, families, and patients are to be ignored—most certainly each group comes into care relationships from different paths—I strongly believe that the *collaborative standard* can take us into a new way of thinking about surrogate decision-making. As we saw, current approaches to surrogate decisions give ‘absolute’ and ‘overriding’ power to families of severely disabled long-term care patients when it comes to long-term care decisions. These standards, however, are hardly the most practical when the majority of time and

care long-term care patients receive comes from their nurses. As long as families retain full control over care situations, both nurse and patient interests are at risk for not being considered fairly. For as we have seen, the *substituted judgment* and *best-interest* standards are difficult to employ without catering, in some respects, to the values or interests of those responsible for making surrogate decisions.

When families are given full authority, in my experience, this denigrates the personhood of nurses because their identities get taken up as ‘things’ in the service of others. Moreover, watching nurses struggle to meet the care requirements that families wanted to be put into practice created ongoing battles on Billy’s floor. Families couldn’t understand why the decisions they made were unable to be implemented and nurses were at a loss for how they were to find the time to increase the attention they were expected to devote to their patients. To me, it makes far better sense to begin, instead, with a standard that looks at the relevant interests of those involved in long-term care relationships and encourages ongoing structured conversations between all parties.

The *collaborative standard*, in calling on all active participants in care relationships to make decisions collectively, can be of little use without establishing the proper setting wherein these deliberations can take place. Engagements in the sort of productive conversations that the standard encourages must be set up in a non-confrontational environment, wherein mutually supportive dialogues can occur. To this end, mapping out such a space requires the possibility of face-to-face interactions which can be made possible, I believe, by adding a non-privileging communicative network into long-term care facilities and health care system.

“Billy’s Network”—as I call the model for care that I am after—involves implementing the *collaborative standard* into practice through the creation of the following ongoing, but necessary, communication arrangements in the long-term care of severely disabled patients in long-term care facilities:

- (1) To every patient, a nurse *representative* is to be assigned so that any concerns families or nurses have regarding the level or quality of care is to exclusively be mediated through this particular individual and relayed back to either group correspondingly.
- (2) Upon arrival, each patient will also be assigned a “care committee” of nurses (of which the nurse representative is a part) who will meet with the family once per month throughout the duration of their loved one’s stay in the long-term care facility.
- (3) Every three months, families will sit down with their committee and the nurse manager to go over changes or suggestions for improving their loved one’s care.

Out of all of these prescriptions, I believe (1) to be the most vital communicative strategy. Having an ongoing nursing contact—someone who is made aware of all care issues—ensures that families’ concerns are given a voice. One of the issues I notice with Billy’s family is that they feel they are being ignored by his nurses—that their concerns are being overlooked. Assigning a nurse representative to each family can aid in creating non-confrontational approaches to care when families are asked to only discuss their immediate concerns with one particular member of the nursing staff. And likewise, this strategy serves the interests of the entire nursing team, as it creates an outlet for nurses to express their concerns regarding familial expectations through the assigned mediator.

Yet, nurses work shift work, and so what is to be done when a family’s nurse representative is not working and the family wishes to speak with her? In times like

these, nurses and families can maintain their dialogue in writing. Families can write down their concerns in a journal that their nurse representative will then read at the beginning of her next shift. Similarly, the nurse representative can explain treatments and other issues of care in the journal so that when families come to visit their loved one, they are made aware of their loved one's condition and the level of care nurses are able to provide.

The call that (2) makes to the establishment of a "care committee" where other nurses and the nurse representative can meet with the family is another essential component to fostering non-confrontational relationships between nurses and families. It is here that fundamental issues of care are to be taken up and surrogate decisions are to be made in accordance with the guidelines set out by the *collaborative standard*. Insofar as patient, nurse and familial interests are to be weighed equally, tensions like that which arose in the family's wanting to increase Billy's physiotherapy would be eased once both sides could sit down to discuss the additional therapy rationally. Bearing in mind that my suggestions are to succeed the cultivation of increased social awareness and reciprocity for nurses and severely disabled patients, it is possible for expectations that exceed the time and resources to which nurses will have access to be vetoed before they place unmanageable care requirements on nurses. Even insofar as nurses are presently trapped to provide care that they cannot adequately accommodate, meetings with the "care committee" can also serve to provide nurses with the means to express their feelings of 'burnout' and the concerns that they have regarding limited resources and staff shortages.

In addition, perhaps when families come to realize that present inadequacies in long-term care are not a function of nurse ‘laziness’ or ‘insensitivity’ but rather a function of insufficient support, families too will take on a more active role in deprivatizing care by drawing attention to the social responsibilities we all have to help improve care.

Finally, the last strategy I suggest is to give families, nurses, and nurse managers the opportunity to sit down and discuss care issues. I believe that in addition to the “care committee”, there needs to be meetings that give families and nurses the chance to voice their concerns to someone who can influence hospital management and suggest resource changes.

By defending each of these strategies, I do not mean to suggest that this is *all* that is needed to bring about better care for long-term care patients. Recall that as I have stressed, little can be done without access to better financial, medical, and educational resources.²⁵ Instead, “Billy’s Network”, in its focus on open and constant communication between health care professionals and families, is a guide for what to do with the additional support insofar as it works to resolve the disagreements in the attitudes that both parties have toward care and negotiates a mutual partnership in the pursuit of improving long-term patient care.

III. Concluding Remarks

Two years ago, I was oblivious to care issues. As an able-bodied young woman who had set foot in a hospital twice for no more than a few hours each time—the first time to have day surgery and the second, to stitch a cut—I never gave a moment’s thought

to what in-patient care was like, let alone what *long-term* in-patient care was like. For me, those thoughts just never crossed my mind and it was only once I began reading about dependency work in my first year of graduate school that I began to seriously think about what life must be like for the families of severely disabled persons and for those entrusted with their care. It is that thinking that brought me to Billy and it is out of my experiences with him that I came to see first-hand the deficient levels of care patients in long-term care facilities are expected to bear. Though I do not anticipate nor expect the wider community to delve as I did into in-depth personal relationships with care recipients, undoubtedly we must introduce some notion of social responsibility with the purpose of improving social responses, awareness, and understanding of care. In my view, beginning with the educational programs that Kittay suggests can help to get members of social communities thinking about the lack of sufficient resources that nurses have access to and how we can go about changing those deficiencies. In increasing community awareness and de-stigmatizing the lives of people with disabilities, it is my hope that universal social recognition can be attained for nurses and their patients so that social attitudes can be changed to deal more supportively with the implications of care relationships. And, once additional support has been set up—once those outside of nurse-patient relationships provide the reciprocity that nurses need to sustain themselves as good care workers—we can move to concentrate on putting social reciprocity (i.e., additional financial and medical resources, increased time off, improved staffing, etc.) to good use by setting up a network of care like “Billy’s Network” An open and on-going

line of communication between families, nurses, and hospital administration is essential to the continuation of good care for long-term patients. For without “Billy’s Network”, nurses are unaware of familial expectations, families are unaware of the care constraints nurses have endured, and administration is unaware of the deficient care a lack of sufficient resources forces nurses to provide. It is time that we begin creating more places to turn for help, for relief, for better care, and also for sharing in extraordinary relationships with patients like Billy.

ENDNOTES

1. See Aiken et al. "Hospital Staffing, organization, and quality of care: cross-national findings" in *International Journal for Quality in Health Care* 2002; 14(1) 5-13.
2. Dialogic negotiations, as described by Lorraine Code in *What Can She Know?* are conversations that invite economically and epistemically advantaged people to enter a conversational format with 'less privileged' participants where no position is absolutely privileged or uncontested and conversations are "open, moving, and resistant to arbitrary closure" (Code, 308).
3. "the work of caring for those who are inevitably dependent"; See Eva Feder Kittay's *Love's Labor*, ix for an explanation as to the source of these requests.
4. For more information, see Chapter 4 for an explanation as to the source of these requests.
5. See p. 9 of their article in the Canadian Bioethics Society Newsletter, February 2004, Vol. 1.
6. O'Hara and Neutel write, "It has been suggested that some type of inventory of values is useful in reconstructing the views of [patients] and guiding proxies in their decisions. Ideally the inventory would be completed by a person before losing the capacity to provide informed consent" (*ibid*).
7. As we saw with Stephen's parents in the Stephen Dawson case.
8. Parentalism, as defined by Jecker et al. in "Separating Care and Cure: An Analysis of Historical and Contemporary Images of Nursing and Medicine", is "an attempt to justify performing (or omitting) an action that is contrary to a patient's expressed wishes, yet judged to be in a patient's best interest" (Jecker et al., 63).
9. As Benjamin and Curtis explain, "A nurse is in an especially difficult position in our health care delivery system. She is expected to be a trustworthy team member who works within a hierarchical system structured from the top down, a hierarchy in which a physician is usually in command. Yet a nurse is expected to work in that health care system as if it were structured from the base up so as to meet assessed needs of the client and the client's family" (Benjamin and Cook, 103).
10. See R. Crawshaw's article "The cost of caring: a view of Britain's delivery of health care". *The Pharos*, 11-15; and P. G. Zimmerman's article "Use of unlicensed assistive personnel: anecdotes and antidotes. *Journal of Emergency Nursing*, 22 (1), 42-48.
11. These distinctions refer to the subordination and marginalization of nurses by doctors and administrators as discussed in Peta Bowden's article: "An 'ethic of care' in clinical settings: encompassing 'feminine' and 'feminist' perspectives" in *Nursing Philosophy*, July 2000, 1(1), 36-49.
12. According to Diemut Bubeck, women's commitment to care traps them in dependency work where "their obligation to meet the needs of people who suffer harm without their assistance

preempts their own freedom and interests" (Bubeck, 25, as cited in Diana Meyers' "Gendered Work and Individual Autonomy" in *Recognition, Responsibility, and Rights* (Fiore R. & Lindemann Nelson H. eds)).

13. Rawls' principles state, "(1) Each person is to have an equal right to the most extensive scheme of basic liberties compatible with a similar scheme of liberties for others" and "(2) Social and economic inequalities are to be arranged so that they are both (a) reasonably expected to be to everyone's advantage, and (b) attached to positions and offices open to all." (Rawls, 1971, 53)
14. See Chapter 5 and my discussion of "Billy's Network".
15. See Fagermoen's findings in her article, "Professional identity: values embedded in meaningful nursing practice", 1997, p. 439.
16. The Department for Professional Employees, AFL-CIO (DPE) acts for 22 unions comprising over four million white collar workers. The Department was contracted by the AFL-CIO in 1977. Retrieved August 20, 2005 from http://www.dpeafcio.org/policy/factsheets/fs_2004_nurses.htm#notes.
17. Linda H. Aiken, PhD, RN; Sean P. Clarke, PhD, RN; Douglas M. Sloane, PhD; Julie Sochalski, PhD, RN; Jeffery H. Silber, MD, PhD, "Hospital Nurse Staffing and Patient Mortality, Nurse Burnout and Job Dissatisfaction," *Journal of the American Medical Association*, Vol. 288, No. 16, October 23-30, 2002
18. Institute of Medicine, *Keeping Patients Safe: Transforming the Work Environment of Nurses*, 2003.
19. Peter D. Hart Research Associates, *The Nurse Shortage: Perspectives from Current Direct Care Nurses and Former Direct Care Nurses*, April 2001.
20. *Keeping Patients Safe*, op. cit.
21. *The Nurse Shortage: Perspectives from Current Direct Care Nurses and Former Direct Care Nurses*, April 2001
22. See Wade's "It Ain't Exactly Sexy" in *The Ragged Edge: The Disability Experience from the Pages of the First Fifteen Years of the Disability Rag*, and "Identity" in *The Disability Rag and ReSource*, 1994.
23. As illustrated in the previous section's example with the medical interventions sought by persons with upper limb phocomelia.
24. It appears that what Silvers is after here is the breaking down of the potentially damaging effects of socializing patients for acceptance—wherein medical interventions can serve to improve the physical 'abnormalities' of patients, but potentially at serious risks to their well-being.
25. To be clear, here I am referring to improved financial resources for both families and nurses, medical resources for patients and nurses (i.e., larger nursing staffs, better and more medical equipment, etc.), and educational resources in the community (i.e., the public commitment that Kittay recommends to youth care programs).

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